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Abstract:

This manuscript sets out the rationale and methods for developing PERSSILAAs' shared vision regarding the screening of frailty and triage of patients through PERSSILAAs' screening protocol. Through a state of the art literature review, this deliverable discusses different definitions and correlates of frailty in order to develop a consensus or "common vision" for the project. Based upon this exploration the consortium agreed to adopt the European Innovation Partnership on Active and Healthy Aging definition. This deliverable also reviews the advantages and disadvantages of the myriad of frailty screening instruments available, again setting out the rationale for selecting suitable tools to assess and triage the population that will be targeted by PERSSILAAs' service model, namely pre-frail, community dwelling older adults age over 65 years. This manuscript explains the rationale for selecting the three key or "core domains" that will be targeted in this project, namely nutrition, cognition and physical function. By establishing suitable screening instruments for these, it also helps clarify the screening and triage pathway for the subsequent validation arm of the project.

In summary, PERSSILAA will target pre-frail community dwelling older adults (>65 years) with a two-step screening protocol. Initial screening will involve a postal/online questionnaire requesting demographic data. Frailty will be assessed with the Groningen Frailty Indicator (a 15-point yes-no questionnaire exploring physical, cognitive, social and psychological components of frailty) with additional information gathered from the INTERMED screen (chronic disease) and three objective home administered tests, the Quick Memory Check (cognitive), the Mini-Nutritional Assessment sections A-F (nutrition) and the KATZ activities of daily living scale and the RAND-36 (physical function). Thus, step one screening will exclude clearly robust or frail patients. Step two will involve more detailed assessment and stratification of patients at risk of progressing to frailty. Pre-frailty will be confirmed using the Fried frailty criteria and patients will be grouped into eight subgroups according to their baseline cognitive (using the Quick Mild Cognitive Impairment screen and observer rated AD8), nutritional (using the Mini-Nutritional Assessment sections G-R), and physical (specific functional tests including the timed up-and-go test) status for evaluation in the validation arm of the PERSSILAA project.

Keyword list: Screening, state of the art, literature review, frailty, functional decline, cognition, nutrition, physical, function

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1.6	08/08/2014	Rónán O'Caoimh (UCC)	Final edit

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1 Executive Summary

The "PERsonalised ICT Supported Services for Independent Living and Active Ageing" project or PERSSILAA is a FP7 funded European project, combining a consortium (eight partners from five countries) from social, medical and technological sciences with industry, academia and end user organisations, with the primary objective of developing an information and communications technology (ICT) based platform to identify and manage community dwelling older adults at risk of functional decline and frailty. With this approach PERSSILAA intends to adhere to the tenants of the European Innovation Partnership on Active and Healthy Aging (EIP on AHA) and increase healthy life span in community dwelling older adults. This document sets out to define a shared vision on screening for frailty and functional decline. It defines frailty and the key factors contributing to its development. It also defines the rationale for selecting the three key or "core domains" that will be targeted in this project, namely nutrition, cognition and physical function. This document also sets out the rationale for selecting the screening instruments chosen to identify older adults at risk. By using key definitions of frailty, agreed by the EIP on AHA, PERSSILAA builds upon current activities within the EIP as well as on the results of previous European projects. It explores state-of-art screening techniques for frailty and each of these three core domains by performing a detailed, evidence-based state-of-art literature review.

The ultimate aim of PERSSILAA is to encourage a move away from the current model of fragmented, reactive disease management towards a preventive, personalized model offered through local community services which is both supported by a proactive team of caregivers and health professionals, and integrated into existing healthcare services. A new systematic approach to screening and subsequent triaging of community dwelling older adults is therefore required. By developing a shared vision on how to screen for frailty and functional decline, PERSSILAA will be able to deliver an evidence-based screening pathway to rapidly and efficiently identify and triage community dwelling older adults who are at risk of these adverse outcomes. This will in turn allow validation of PERSSILAAs' technical service infrastructure.

In practice, the PERSSILAA service model will be validated in approximately 350 community dwelling older adults (age over 65 years) recruited in Enschede (the Netherlands) and Campania (Italy) regions. A clear vision on the baseline characteristics of the subjects to be screened will be developed in this deliverable, in order to target interventions, thereby ensuring system efficiency and validity, and ultimately end user acceptance. Using the principles of screening developed in this review, evidence based outcomes will be selected which will provide meaning to the subsequent results of the validation study. These outcomes include changes in the three core domains, nutrition, cognition and physical function as well as changes in measures of quality of life (QOL) and risk of adverse outcomes including hospitalisation and institutionalisation. In addition, the economic benefits of PERSSILAA will be assessed in order to understand to what extent PERSSILAA can improve efficiency with the subsequent aim of building business models for future sustainable implementation while simultaneously driving the development of next generation screening and management services for community dwelling older adults in the European Union (EU). The use of clearly defined definitions and study populations, set out in this deliverable, will also increase the external generalizability of the project and allow the development of recommendations that will feed into EU guidelines on the management of frailty and functional decline.

The accepted definition of frailty used in PERSSILAA is that derived from the EIP on AHA. This defines frail older adults as those "who are at increased risk for future poor clinical outcomes, such as the development of disability, dementia, falls, hospitalisation, institutionalisation or increased mortality". PERSSILAA will use this definition to help identify patients who have already become frail, those who are at increased risk of frailty (defined as the pre-frail) and those who are robust (non-frail). Given that there is on-going debate as to whether frailty is reversible or not and given that the objectives of the EIP on AHA are to prevent functional decline and frailty, rather than targeting those who are already frail or those who have not developed risk factors or signs of frailty (robust patients), PERSSILAA aims to identify those who are pre-frail.

Thus, based upon the evidence presented in this deliverable, supported by a detailed evidence-based state of the art literature review, PERSSILAA will screen for frailty with a two-step pathway using a sequential design for its screening protocol. Step one will be consist of self-reported screening, while step two consists of rater-observed assessment. In step one, older adults will be invited to participate through postal or online questionnaires. In this way clearly frail or robust older adults will excluded. In step two, pre-frail older adults will be identified.

Step one will utilize a 15-point yes-no questionnaire exploring physical, cognitive, social and psychological components of frailty called the Groningen Frailty Indicator (GFI). Demographic data including patients' age, gender, education, socioeconomic class, social isolation & social supports, alcohol and smoking history, computer Literacy, depression, Body Mass Index, QOL, medical comorbidities, polypharmacy, history of falls and hospitalization will also be collected. Additional frailty screening data will be gathered from the INTERMED. Thus, patients with a GFI score ≥4 (clearly frail) and or an INTERMED score <15 will be excluded. In addition, individual domains will be screened to further evaluate and exclude subjects based on the likelihood of normal cognitive (no complaints of memory loss & Quick Memory Check score >50/100), nutritional (Mini-Nutritional Assessment section A-F score >12), and physical (The Short-form 36 physical functioning SF-36-PF, subscale score <61 or KATZ activity of daily living scale score >4) status. Remaining patients will then be included for second level screening. Step two will refine the screening process with a face-to-face assessment. Any remaining frail and robust older adults will be identified and excluded using the Fried frailty criteria (score of 0 or ≥3). Pre-frail patients (those remaining after the Fried criteria are applied) will then be assessed using the following assessment instruments: for cognition, the Quick Mild Cognitive Impairment screen and the observer rated AD8, for nutrition, the Mini-Nutritional Assessment sections G-R and for physical function, specific functional tests including the timed up-and-go test, by a local expert panel and grouped into eight subgroups based upon their cognitive, nutritional and functional status.

Thus, pre-frailty will be defined as mild dysfunction in any of the three domains: cognition (i.e. a Q*mci* score between 40-60, adjusted for age and education, with a history of cognitive decline, but AD8 <2), nutrition (MNA G-R of between 7-23.5) and physical (selected cut-off scores on a battery of physical assessments, adjusted for age and gender), and a Fried Frailty score of 1 on 2. Based upon this assessment pathway, evaluating each of the core domains targeted by the PERSSILAA service module, patients will be triaged into eight subgroups, ready for inclusion in the validation arm of the study.

2 About this document

This document explains the rationale behind the screening component of the PERSSILAA project. A key component of PERSSILAA is the development and validation of a new service model, to screen for and prevent frailty and functional decline in community dwelling older adults. This document explores the nature of frailty and functional decline as pertains to older people in the EU, focusing on three key domains: nutrition, cognition and physical function, in order to develop remote service modules to simultaneously screen, monitor and train.

- Screening: Easy to use tools to assess an individual's health status.
- Monitoring: Unobtrusive monitoring of an individual's everyday functioning.
- Training: Remotely available health promotion programs.

As PERSSILAA is designed to innovate the way our current care services are organized and delivered, this document explores the up-to-date screening techniques and instruments currently available to identify community dwelling older adults at risk of frailty and functional decline.

2.1 Role of the deliverable

This deliverable, WP D2.1, is part of work package two (WP2) and describes the development of a shared vision for the screening and prevention of frailty. As frailty has many potential definitions this deliverable operationalizes it for the purpose of the PERSSILAA project. This deliverable also describes and operationalizes the three core domains: nutrition, cognition and physical function, which together form the three screening components of the project.

Overall, this deliverable defines a shared vision of screening for and prevention of frailty and functional decline in PERSSILAAs' target population, community dwelling older adults.
Thus, in summary WP D2.1 defines:

- A shared vision on Frailty;
- Different screening instruments for frailty and the three core domains: nutrition, cognition and physical function;
- A triage protocol to assign patients to more detailed screening pathways: two-stage screening.

2.2 Relationships to other PERSSILAA deliverables

This deliverable provides a key platform for the development of other deliverables in WP2, including D2.2.1, feeding directly into the development of preliminary service case scenarios and use cases. It also informs the development of WP D2.3.1, which describes the technical requirements and architecture of the project. The results of this deliverable will determine the scope of the specifications discussed in D2.3.1. This deliverable is also strongly related to T3.1 which describes the technical and practical development of the screenings protocol, based upon the definitions and validated screening instruments chosen in this deliverable. In addition, this deliverable is strongly related to WP5 wherein each of the PERSSILAA solutions will be validated. Specifically, the shared vision of frailty, screening and triage to training services generated in this deliverable, provides key criteria to aid in the selection the validation cohort for the validation study. It also provides a template for selecting suitable outcome measures that will be screened on entry to the study and monitored over the course of follow-up.

2.3 Structure of this document

This document is divided into three parts:

1. The development of a shared vision on Frailty;
2. The selection of the different screening instruments for frailty and each of the different core domains in the PERSSILAA project: nutrition, cognition and physical function;
3. The development of a triage protocol to guide the screening (two-step) and the subsequent allocation of patients to each of the different service modules.

The remainder of this document is structured as follows:

- Section three provides a general introduction to frailty.
- Section four describes the methodologies used to come to a shared vision on frailty, as well as well as the selection of the screening instruments for frailty in general and each of the three core domains: nutrition, cognition and physical function.
- Section five presents the shared vision and the chosen screening instruments.
- Section six provides a conclusion.
- Section seven provides a discussion of future work.
- All proposed screening instruments are included in the Appendix 1.

3 Introduction

The number and proportion of older adults is increasing internationally, particularly within the EU (WHO 2002). Frailty is associated with increasing age such that by the age of 90 years approximately 30% of older adults can be considered frail (Ahmed et al). Estimates vary among community dwelling older adults depending on populations studied, with prevalence rates reported from as low as 7% (Fried et al 2001) to as high as 40-50% (Slaets et al), (Metzelthin et al) in those aged over 65 years. A recent systematic review of the prevalence of frailty in community dwelling older adults estimated that the overall weighted prevalence was 10.7% (Collard et al). Several other factors impact upon the prevalence of frailty including gender. For example, 16% of women in the United States between 65 and 79 years of age are frail, (Woods et al 2005) compared with <10% of males. Similar gender disparity has been demonstrated in the EU (Syddall et al) (8.5% female compared with 4.1% of males aged between 64 and 74 years of age). Within the EU the prevalence of frailty in community-dwelling older adults aged over 65 years varies between studies with data suggesting that between 5.8% and 27.3% are frail and a larger number, approaching 60%, are pre-frail (Santos-Eggimann et al). Frailty is associated with the development of adverse outcomes. Death, disability, and institutionalization are common consequences for frail older adults (Sternberg et al). Frailty increases mortality, increasingly so as we age (Song et al). Frailty is also expensive (Robinson et al) and in light of recent economic challenges, it represents a cost that will be difficult for future generations to accommodate. To date, multiple different screening instruments are available to identify frailty (de Vries et al).

Despite the growing number of frailty screening tools, few if any, screening programs for the identification of community dwelling older adults at risk of frailty and functional decline have been developed. To our knowledge, none have been implemented in the EU. Indeed, no integrated screening and management strategy has been developed or validated in clinical practice. However, combinations of complex interventions, delivered in the community, can reduce institutionalisation and hospitalization (Beswick et al), while comprehensive geriatric assessment (CGA), involving broad interdisciplinary assessment to improve and manage all aspects of an older persons` care, has been suggested to reduce adverse (Beswick et al). To date however, there is limited evidence that interventions delivered in the home setting can prevent adverse outcomes (van Haastregt et al).

The EIP on AHA action plan concerning the prevention and early diagnosis of frailty and functional decline in older people (action plan A3) [EIP on AHA] states that:

“Innovation should play a key role in rethinking and changing the way we design and organise our society, environment and finance, in order to deliver health and social care services to face challenges posed by ageing trends”.

With respect to the screening for frailty action plan A3 states that:

“Successful prevention of frailty and functional decline requires more knowledge about the risk factors. The ability to stratify is particularly needed. Eventually it will result in better definitions of risk groups and therapies and interventions that can be offered earlier, more specific and more tailored”.

This lies at the heart of the PERSSILAA philosophy and is the central goal of this deliverable.

Thus, this deliverable is concerned with the identification of factors influencing the development of functional decline and frailty, particularly in the three core domains identified a priori i.e. nutrition, cognition and physical function, in order to build an integrated multidimensional screening pathway for PERSSILAA. By identifying suitable screening instruments with sufficient accuracy (sensitivity and specificity) to identify the precursors and markers of frailty, this review will set the stage for the rest of the project. This review sets out the rationale for developing clear evidence based pathways to screen and triage patients into non-frail, pre- frail and frail. It further expands upon the rationale behind the selection of each screening instrument by examining the characteristics including advantages and disadvantages of each. This review also sets out to explain the reason for triaging patients according to their level of frailty and for the selection of screening instruments for each of these three core domains.

Ultimately this will lead to the development of a shared vision of frailty and the creation of clear and practical multi-dimensional screening techniques that can inform the development and validation of personalised ICT supported services to prevent functional decline and frailty in community dwelling older adults.

4 Methods

In this section, we discuss the different methods applied in the selection of the definition of frailty, the screening tools for frailty and for each of the core screening domains: nutrition, cognition and physical function, and finally a triage protocol for the subsequent allocation of patients to tailored service modules.

4.1 Methodology for creating a shared vision on frailty

The development of a shared vision regarding the concept of 'frailty' started from a review of the state of the art of frailty screening. The literature was searched using different, scholarly libraries (including MEDLINE, Web of Science, EMBASE, PsycINFO, Picarta, Google Scholar, and the Cochrane Controlled Trial Register). The search terms were as follows: Elderly, aged, frailty, pre-frailty, definition, consensus.

If applicable to the key word, Medical Subject Heading (MeSH) terms were included and then combined with the search. In addition, references from papers found in the initial search were checked to find additional studies. As frailty is a relatively new term, originally defined according to Linda Frieds definition of frailty from the Cardiovascular Health Study Index [Fried 2001], articles were included from 1990 to present. Articles older than this were excluded. Only articles written in English or Dutch were included.

Once all accepted definitions of frailty were found, the results were presented to the consortium for discussion in order to reach a consensus. The results of the discussions including the rationale for selecting an appropriate definition of frailty, along with each of the screening instruments are discussed in section 5.1. The methodology for selecting the screening tools is discussed in section 4.2.

4.2 Methodology for the selection of screening tools

The selection of the screening tools for frailty and the cognitive, physical and nutritional domains was also based upon an evidence-based review of the state of art of screening. A literature review was conducted and once again different, scholarly libraries (including MEDLINE, Web of Science, EMBASE, PsycINFO, Picarta, Google Scholar, and the Cochrane Controlled Trial Register) were searched. Search terms for the frailty screening instruments were: screening, instrument, screen, sensitivity, specificity, accuracy, frailty, pre-frailty. Similar inclusion and exclusion criteria to the search criteria for definitions of frailty were used. Relevant search terms were also entered to identify suitable screens for nutrition, cognition and physical function. The most widely studied instruments were then considered as part of the review process prior to selection and integration into PERSSILAAs' frailty screening pathway.

Once all possible screening tools were available, the results were again presented to the consortium for discussion in order to reach a consensus. In order to select the most appropriate instrument for use in PERSSILAA, the following requirements were applied:

1. The instrument should be reliable and valid;
2. The instrument should be suitable (validated) for an older population;
3. The instrument should have been used in an European setting;

4. The instrument should be sensitive and specific (i.e with a high level of accuracy);
5. The instrument should be accompanied by an overview of outcome scores and cut-off points that specify the likelihood of an individual having a condition (in terms of general frailty, or in terms of one of the three domains), i.e. separating normal from impaired.
6. The instrument should also be easy and quick to administer (and if possible self-administered).

The rationale for selection and the results of these discussions are presented in sections 6 to 8.

4.3 Methodology for developing personas

Personas were developed to create a reference point for each possible outcome of the screening process. Personas are fictitious persons, reflecting the characteristics of a larger population. By formulating the characteristics of any subgroup into one person, it may become easier for people to discuss the characteristics of that subgroup. After all, a persona is more tangible and easier to understand. In technology design, personas have been shown to ease the discussion when designing novel services, and to increase the focus on the human-centeredness aspect of design (Cooper et al).

The personas developed for PERSSILAA were derived from principles described by LeRouge et al (2011). In all, eight personas were created, reflecting all possible outcomes of the frailty screening process. Each were based on different combinations of the physical, cognitive and nutritional domains. In addition, other relevant factors, including demographics and relevant background history were incorporated into the personas (e.g. some individual personas were declared “handy with technology”, while other personas were deemed technophobic). Each personas individual attributes were developed using a translation table, as suggested by Van Velsen et al. The translation tables are presented in Appendix 1.

4.4 External review of the screening approach

The combined screening tools should assess an individual’s frailty level, including his or her physical, cognitive and nutritional status, based upon each of the relevant screening instrument cut-off scores. In order to make certain that (a) the selected instruments will successfully assess these issues, and (b) the selected instruments will be accepted by the different caregivers involved, an external review by medical experts was organized. Seven experts were sent an overview of the screening procedure (incorporating the selected instruments and the screening protocol) and asked to give their opinion on:

1. The quality of the individual screening instruments;
2. The quality of the screening procedure as a whole.

The request including explanation and questions provided to the expert panel is discussed in Chapter 11 and the survey used can be found in the Appendix 4. All correspondence was done via e-mail to limit delay and prevent inconvenience to the external reviewers.

5 Results

5.1 A shared vision on frailty

Frailty is a concept that has been defined in a multitude of ways in recent years. Despite the increasing interest and importance of research into frailty no consensus on a definition of frailty has yet been accepted. The goal of this section, therefore, will not be to provide the reader with an exhaustive overview of the ways in which frailty has been defined. Rather, the goal is to illustrate the ways in which the concept can be defined, leading up to a definition that is shared by the different partners in the PERSSILAA project, and that reflects the objectives of the PERSSILAA service model.

The original definition of frailty originates from the model described by Fried et al (Fried 2001). According to the definition, derived from the Cardiovascular Health Study (CHS), an individual is classified as frail if he or she meets three or more of the following five criteria:

- Weight loss (>5% in last year);
- Exhaustion;
- Weakness (decreased grip strength);
- Slow walking speed (>6 to 7 seconds for 15 feet);
- Decreased physical activity (males <383 kilocalories); females <270 kilocalories).

Since this original definition, frailty has been defined as a multi-factorial state, correlating with vulnerability, disability, co-morbidity, and self-reported health status. In other words: frailty is "[a] state of vulnerability defined by many factors" (Rockwood, 2005). The Canadian Initiative on Frailty and Ageing, classified definitions of frailty into four classes: (i) physiological definitions, (ii) definitions based on frailty as a complex syndrome, (iii) frailty based on a balance model (which adds social elements) and (iv) frailty on the basis of a geriatric syndromes, such as delirium and /or falls. Despite this, no single definition of frailty is widely accepted (Sternberg et al). Some of the competing definitions of frailty can be found below:

> "[A] physiological syndrome characterised by decreased reserve and diminished resistance to stressors, resulting from a cumulative decline across multiple physiological systems, and causing vulnerability to adverse outcomes" (The American Geriatrics Society).

> "[A] medical syndrome with multiple causes and contributors that is characterized by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death."(Morley et al)

> "A clinically recognizable state of increased vulnerability resulting from aging-associated decline in reserve and function across multiple physiologic systems such that the ability to cope with everyday or acute stressors is comprised." (Xue et al 2011).

> "[Frail elderly are] older adults who are at increased risk for future poor clinical outcomes, such as development of disability, dementia, falls, hospitalisation, institutionalisation or increased mortality" (EIP on AHA)

More recently a major international consensus group defined frailty as “medical syndrome with multiple causes and contributors that is characterized by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death.” (Morley et al). The consensus group that worked at the definition as presented by Morley (2013) suggested that physical frailty should be considered reversible. However, this reversibility has been highly debated in the scientific community.

In the PERSSILAA project, frailty is considered to be multi-faceted, as reflected by the decision to divide frailty in the subdomains of nutrition, cognition and physical function. After consensus discussion between partners in the consortium the EIP on AHA definition of frailty was selected. The EIP on AHA definition of frailty was selected for several reasons. Primarily it was selected as the overall objective of the PERSSILAA project mirrors the headline objective of the EIP, namely the development and implementation of sustainable multimodal interventions for the prevention and comprehensive management of functional/cognitive decline and frailty (EIP on AHA). Given that there is on-going debate as to whether frailty is reversible, as suggested by Morley (Morley et al) or not, and given that the objectives of the EIP on AHA are to prevent functional decline and frailty, rather than targeting those who are already frail or those who have not developed risk factors or signs of frailty (robust patients), PERSSILAA aims to identify those who are pre-frail. Again PERSSILAA uses the guidelines adopted by the EIP on AHA, which defines frail older adults as those meeting one or two of the Fried five criteria, derived from the CHS, i.e. weight loss (>5% in last year), exhaustion, weakness (decreased grip strength), slow walking speed (>6 to 7 seconds for 15 feet), and decreased physical activity. Pre-frailty is when one or two of these characteristics are met. Otherwise, the person is classified as robust.

Characteristics and Correlates of Frailty:

This section reviews the evidence for the demographic and other patient characteristics associated with the development of frailty. In order to develop a rounded and statistically sound definition of frailty for the subsequent validation study it is important to understand and collect relevant baseline patient characteristics. Several demographic factors and co-morbidities are associated with frailty including advanced age (Song et al), and female gender (Walston et al), (Puts et al). These results are summarised in Table 1 and Table 2 (medical comorbidities). Although age is traditionally associated with frailty, chronological age added very little to the explained variances of all outcomes once frailty was included [Schuurmans]. Frailty is independent of age in defined populations including those undergoing haemodialysis (McAdams-DeMarco et al). However, above a certain age, estimated to be 95, virtually everyone becomes frail (Song et al). This age cut-off, calculated from mortality data, is the point at which the phenomenon of “mortality cross-over” occurs, the point at which it is hard to identify individuals at risk of factors such as mortality using traditional markers (gender, social class, race etc) and where some factors associated with mortality at a younger age can even become protective (e.g. body mass index). Older frail females have a higher mortality than males (Puts et al). Frailty is not a benign state but is associated with an increase in adverse events including mortality and risk of hospitalisation (McAdams-Demarco et al). Thus, frailty identifies a heterogeneous group of individuals with an increased risk of adverse outcomes. Frailty also predicts readmission to hospital and ED visits among older adults (Salvi et al). As can be seen in Table 1 age, gender, education, socioeconomic class, social isolation & social supports, alcohol and smoking history, computer Literacy, depression, Body Mass Index, quality of life (QOL), medical comorbidities, polypharmacy, history of

falls and hospitalization are all associated with frailty. In order to develop an accurate and detailed picture of each participant including in the PERSSILAA projects each of these variables will be collected at baseline and at then at varying intervals at follow-up throughout the validation study. Operational definitions, the type of instrument used to record them and the frequency of follow-up assessment of each variable are presented in Table 3. Different choices of screening tools for each of these variables including their individual strengths and weakness are presented in Table 4.

In summary, the PERSSILAA consortium agreed to use the EIP on AHAs definition of frailty based upon the Fried Frailty Criteria. As frailty is correlated with multiple demographic factors, PERSSILAA will record several correlates of frailty including patients' age, gender, level of education, socioeconomic class, social supports, history of alcohol and smoking history, computer Literacy, depression (with the ABCS Depression scale [Molloy et al 2006]), Body Mass Index, QOL (with the European Quality of Life–5 Dimensions questionnaire or EQ-5D) (Euroqol), medical comorbidities (with the Charlson co-morbidity index (Charlson), polypharmacy (simple count), history of falls and hospitalization.

Table 1 - Table presenting different demographic factors associated with the development of frailty detailing their relationship with frailty and the justification for their inclusion in PERSSILAA.

Factor	Relationship with Frailty & Justification for Inclusion in PERSSILAA
Age	Ageing is associated with increasing frailty. (Fulop T, Larbi A, Witkowski JM, McElhaney J, Loeb M, Mitnitski A, Pawelec G. Aging, frailty and age-related diseases. Biogerontology. 2010;14: 547–563.) In all, there is a 4.0% to 17.0% (mean 9.9%) prevalence of physical frailty in community dwellers aged >65, and the prevalence increases markedly in those > 80 years of age(Collard JM, Boter H, Shoevers RA, Oude Voshaar RC. Prevalence of frailty in community-dwelling older persons. JAGS 2011 2012, 60:1487-1492.). Increased recovery time with ageing leads to an accumulation of deficits over time (Mitnitski A, Song X, Rockwood K (2013) Assessing biological aging: the origin of deficit accumulation. Biogerontology 14. doi:10.1007/s10522-013-9446-3)
Gender	Women (9.6%) are twice as likely as men (5.2%) to be frail (Collard JM, Boter H, Shoevers RA, Oude Voshaar RC. Prevalence of frailty in community-dwelling older persons. JAGS 2011 2012, 60:1487-1492.). Frailty is associated with greater mortality in woman compared with men, independent of disability and chronic disease (Puts MT, Lips P, Deeg DJ. Sex differences in the risk of frailty for mortality independent of disability and chronic diseases, JAGS 2005;Jan, 53(1):40-7.)
Education (Socioeconomic status or class)	Evidence in females that low education and income are associated with frailty regardless of ethnicity.(Szanton SL, Seplaki CL, Thorpe RJ Jr, Allen JK, Fried LP. Socioeconomic status is associated with frailty:the Womans Health and Aging Studies. J Epidemiol Community Health 2010;Jan;64(1):63-67). Some data are inconsistent with some studies finding no differences in the prevalence of frailty by level of education, occupation or place of residence. (Garcia-Garcia FJ et al. The prevalence of frailty syndrome in older population from Spain. The Toledo Study for Healthy Aging. J Nutr Health Aging. 2011 Dec 15(10):852-6.)
Social isolation	High levels of frailty risk factors in those living alone, particularly cognitive impairment. (Bilotta C, Case A, Nicolini P, Mauri S, Castelli M, Vergani C. Social vulnerability, mental health and correlates of frailty in older outpatients living alone in the community in Italy, Ageing Ment Health 2010, May;14(8):1024-36.)
Alcohol	Mixed results seen, recent paper suggest reverse J shaped curve with higher levels of frailty in those with low and high alcohol intake, lower levels in those with moderate intake (Seematter-Bagnoud L, Spagnoli J, Bula C, Santos-Eggiman B. Alcohol use and frailty in community dwelling older persons aged 65 to 70 years. J Frailty Ageing 2014;3(1):9-14.)
Smoking	Smoking results in poor healthcare outcomes. Deficits accumulated due to smoking can be captured using frailty indexes suggesting that there may be an association. It's a dose dependent relationship with greater frailty in heavy smokers (Hubbard RE, Searle SD, Mitnitski A, Rockwoood K. Effects of smoking on the accumulation of deficits, frailty and survival in older adults: a secondary analysis from the Canadian Study of Health and Aging. J Nut Health and Ageing 2009,May:13(5):468-72.) Survival advantage for females lost if smokers (Wang C, Song X, Mitnitski A, Yu P, Fang X, Tang Z, Shi J, Rockwood K. Gender differences in the relationship between smoking and frailty:results from the Beijing Longitudinal Study of Ageing. J Gerontol A Biol Sci Med Sci 2013, Mar; 68(3):338-46.)

(Continuation of Table 1)

Factor	Relationship with Frailty & Justification for Inclusion in PERSSILAA
Depression	Bi-directional relationship with depression being a risk factor for frailty and vice-versa. (Mezuk B, Edwards L, Lohman M, Choi M, Lapane K. Depression and frailty in later life: a synthetic review. Int J Geri Psych 2013 Jul;28(7):766-7.)
Body Mass Index (BMI)	BMI shows a U shaped relationship to frailty with very low and very raised BMI is associated with markers of frailty. (Hubbard RE1, Lang IA, Llewellyn DJ, Rockwood K J. Frailty, body mass index, and abdominal obesity in older people. Gerontol A Biol Sci Med Sci. 2010 Apr;65(4):377-81.)
Quality of life	Frailty negatively affects QOL (Strawbridge WJ, Shema SJ, Balfour JL, Higby HR, Kaplan GA. Antecedents of frailty over three decades in an older cohort. J Gerontology 1998;53b(1)S9-16.)
Medical Comorbidities	Multiple medical conditions are associated with frailty, see separate table.
Falls	Complex interaction between falls & frailty: More than the antecedents or associates of frailty but also seen as a manifestation of complex system failure. (Nowak A, Hubbard RE. Falls and frailty: lessons from complex systems J R Soc Med. Mar 1, 2009; 102(3): 98–102). Frailty is an independent predictor of falls in men. (Nelson JM, Dufraux K, Cook PF. The relationship between glycemic control and falls in older adults. J Am Geriatr Soc. 2007 Dec; 55(12):2041-4.) and women (Ensrud KE, Ewing SK, Taylor BC, Fink HA, Stone KL, Cauley JA, Tracy JK, Hochberg MC, Rodondi N, Cawthon PM, Study of Osteoporotic Fractures Research Group Frailty and risk of falls, fracture, and mortality in older women: the study of osteoporotic fractures. J Gerontol A Biol Sci Med Sci. 2007 Jul; 62(7):744-51.)
Polypharmacy	The use of five or more medications can be defined as polypharmacy and increases risk of developing frailty (Gnjidic D, Hilmer SN, Blyth FM, Naganathan V, Waite L, Seibel MJ, McLachlan AJ, Cumming RG, Handelsman DJ, Le Couteur DG. Polypharmacy cutoff and outcomes: five or more medicines were used to identify community-dwelling older men at risk of different adverse outcomes. J Clin Epidemiol. 2012 Sep;65(9):989-95.).

Table 2 - Medical co-morbidities associated with the development of frailty.

Co-morbidity	Reference
Heart Failure	Afilalo J et al. Frailty in patients with cardiovascular disease: Why, when and how to measure. Current Cardiovasc Risk Rep 2011; 5:467-472.
Cancer	Ruiz M et al. Management of elderly and frail elderly patients: the importance of comprehensive geriatric assessment and the need for guidelines. Am J of Med Sci: 2012.
Renal Failure	Shilpak MG et al. The presence of frailty in elderly persons with chronic renal insufficiency. Am J of Kidney Disease 2004;43:861-867.
HIV (AIDS)	Desquilbet L et al. HIV-1 infection is associated with an earlier occurrence of a phenotype related to frailty. J Geront A Biol Sci Med Sci 2007;62:1279-1286.
Diabetes	Sinclar A et al. Diabetes Mellitus in older people: Position statement on behalf of the international association of gerontology and geriatrics (IAGG) the European Diabetes Working Party for older people. JAMDA 2012
Peri-operative	Partridge JS et al. Frailty in the older surgical patient: A review. Age and Ageing 2012;41:142-147.

Table 3 - Operational definitions of the additional frailty variables including the type of instrument used to record them and the frequency of follow-up assessment for each variable during the validation study.

Factor	Operational Definition	Instrument in PERSSILAA	Frequency
Age	Age derived from date of birth	Brief initial questionnaire	Baseline only
Gender	Male or female	Brief initial questionnaire	Baseline only
Education (Socioeconomic status or class)	Final level of formal education completed. Primary, secondary or third level. Principal occupation/employment.	Brief initial questionnaire	Baseline only
Social isolation & social supports	Who lives with the subject and what community supports they receive. If the person receives supports, describe the nature and frequency of assistance the person receives. Support describes persons or groups, who regularly provide assistance. It is divided into formal and informal care. Provide an estimate of the number of days per week and hours of care/support provided daily. This includes an estimate of the total number of hours of care/support received per week, formal and informal. *Informal care:* People who provide care or assistance that are not professional caregivers, for example a neighbour who delivers groceries. Maybe family/partner, friend, neighbour or Other (please state). *Formal care:* person is attending a day care centre, or receiving Meals on Wheels (cooked food delivered to house).	Brief initial questionnaire	Baseline + Interval
Alcohol	Units of alcohol consumed per week (1 unit is 1 standard drink i.e. 1 small glass of wine, half a pint of beer).	Brief initial questionnaire	Baseline + Interval
Smoking	Number of cigarettes smoked / day/ number of years (Pack years)	Brief initial questionnaire	Baseline + Interval
Computer Literacy	Self-rated ability with technology particularly with computers/smart phones/tablets. Patient preference for use of ICT.	Brief questionnaire	Baseline only

(Continuation of Table 3)

Factor	Operational Definition	Instrument in PERSSILAA	Frequency
Depression	State of low mood and aversion to activity that can affect a person's thoughts, behaviour, feelings and physical well-being [Salmans]. Symptoms include sadness, hopelessness, emptiness, worthlessness, helplessness, guilt and irritability. Signs include loss of interest, reduced concentration, fatigue, reduced or excessive appetite, insomnia, reduced libido and suicidal tendencies. Aches, pains or digestive problems that are resistant to treatment may be present [NIH mental health].	ABC Depression screen [Molloy 2006]	Baseline only
Body Mass Index (BMI)	Based upon weight and height based upon according to the formula: (BMI) = weight (kg) Height (m) x Height (m)	MNA	Baseline + Interval
Quality of life (QOL)	Self-reported QOL	EQ-5D [Euroqol]	Baseline + Interval (e.g. 3/12) End-point
Medical comorbidities	List all medical co-morbidities with option to incorporate into a comorbidity score such as the Charleson Co-Morbidity Index.	Brief initial questionnaire	Baseline only
Polypharmacy	Absolute number	Brief initial questionnaire	Baseline only
Falls	History of falls in the last one-year, absolute number. Interval yearly assessment. "Have you fallen in the last year?"	Brief initial questionnaire	Baseline + Interval
Hospitalisation	Self-reported admissions to hospital in the last one-year, absolute number. "Have you been admitted to hospital in the last year?"	Brief initial questionnaire	Baseline + Interval

Table 4 - Different choices of screening tools for these variables, including the strengths and weakness, of each of these instruments.

Factor	Test to define/quantify/assess	Advantages to inclusion	Disadvantages to inclusion
Age	Basic demographics	Easy to assess with simple questions	Nil
Gender			
Education (Socioeconomic status or class)			Inconsistent associations with frailty
Social isolation	Basic demographics (Living alone Yes/NO) Ask re: community supports		
Alcohol	Quantification in units	Easy to assess	Unclear accuracy may need collateral
Smoking	History, pack years	Easy to assess	
Body Mass Index (BMI)	Requires Weight and Height	Easily available from estimate in the MNA	Unclear accuracy unless measured directly.
Quality of life	EQ-5D [Euroqol] Or SF-36	Required at baseline	Important marker to assess meaningful change.
Medical comorbidities	Charleston Co-morbidity Index or Cumulative Illness Rating Scale		
Polypharmacy	Use of validated instrument e.g. STOPP-START Or Simple count	Provides useful information on extent of co-morbidities	Difficult to assess accurately unless ready access to GP/Pharmacy records.
Falls	TUG test	Well validated. Short and easy to administer	

(Continuation of Table 4)

Factor	Test to define/quantify/assess	Advantages to inclusion	Disadvantages to inclusion
Depression	Geriatric Depression Scale [Yesevage]	GDS-SF widely validated. High specificity with a cut-off score of >7/15 [Marc].	Takes longer than other tests. High specificity cut-off lowers sensitivity.
	ABC Depression screen [Molloy]	-Very short administration time. -As accurate as longer tests. -App available.	-Less widely validated (Canada), Ireland (unpublished).
Co-Morbidity	Charleson Co-morbidity Index [Charlson]	-Well-validated measure. -Widely used in research.	-Poor predictive validity, particularly among older adults [Testa]. -Fails to incorporate medical conditions like Parkinson's disease, multiple sclerosis and inflammatory bowel disorders, which may contribute to comorbidity/frailty. -Limited detail. -Unclear relevance in older adults. -List co-morbidities and weights them only. -Permission required.
	Cumulative Illness Rating Scale	-Geriatric specific version (CIRS-G) available. -Assesses systems, scoring from 0 (no problem) to -Clear scoring instructions available. -Increasingly well validated.	-Long -Complex & may require specialist assessment. - Possibly impractical to score.

5.2 Screening for frailty in general

5.2.1 Overview of the existing instruments

There is a wide selection of screening instruments for frailty (see Tables 5-7). Usually, frailty is identified by means of comprehensive geriatric assessment. Such an assessment involves multiple medical disciplines with the goal to improve and manage all aspects of an older person's care. However, short screening tools may be suitable as an alternative for such a comprehensive assessment.

The instruments available differ on the following points:

- Observer vs. self-rated. The questionnaires are either completed by the older person him/herself, or are completed by a trained caregiver or volunteer;
- Static frailty vs. dynamic frailty. The questionnaires can be assess frailty at a single point in time (static frailty), or can assess it between two points in time (dynamic frailty).
- Non-frail, pre-frail and frail. Questionnaires can either classify a person as being frail or not, or can provide a more granular outcome in terms of non-frail, pre-frail or frail.

Table 5 shows the most widely-used screening instruments for assessing frailty and their characteristics. Table 6 explains the advantages and disadvantages associated with each instrument.

Table 7 presents the variables contained within each screen.

Table 5 - Comparison of different frailty instruments considered for use in PERSSILAA including the Tilburg Frailty Indicator (TFI), Groningen Frailty Indicator (GFI), INTERMED for the Elderly Self-Assessment (IM-E-SA), SHARE-Frailty Instrument (SHARE FI), Frailty Index (FI), Sherbrooke Postal Questionnaire (SPQ), Clinical Frailty Scale (CFS), & the Cardiovascular Health Study (CHS) Index.

Frailty Screen	Type of screen	No of items	No of frailty domains	Cognition assessed	Physical frailty assessed	Nutrition assessed	Validated in community sample	Cut-off scores available	Sensitivity	Specificity
GFI	Self-rated Questionnaire	15	7	+	+	-	+	≥4 Mod-severe frail)	71% (Develop disability)	63%
TFI	Self-rated Questionnaire	15	6	+	+	-	+	≥5 Frail	62% (Develop disability)	71%
IM-E-SA	Self-rated Questionnaire	20	na	-	+	-	+	≥15 Frail	-	-
SPQ	Self-rated Questionnaire	6	4	+	+	-	+	>1 Frail	75% (Functional decline)	52%
EARLI	Self-rated Questionnaire	6	4	+	+	-	+ (GP in UK)	≥6 (ED admission < 1yr)	64%	64%
SHARE-FI	Observer rated Questionnaire & clinical :software	6	2	-	+	+	+ (11+ EU countries)	Non-frail Pre-frail Frail	-	-
FI	Observer rated: software	70	36	+	+	+	+ Canada	Non-frail Pre-frail Frail	-	-
CFS	Observer rated: clinical	9	Overall clinical phenotype	- (indirect)	+	-	+	<3 Non-Frail 4 Pre-frail ≥5 Frail	0.70-0.75 accuracy for mortality	
CHS (Fried)	Observer rated: Questionnaire & clinical	2	5	-	+	+	+	0 Non-frail 1 Pre-frail ≥3 Frail		

Table 6 - Comparison of the advantages and disadvantages of different frailty screening instruments.

Frailty Screen	Advantages	Disadvantages
GFI	- Widely used in the Netherlands. - Available in English, Dutch and Italian - High internal consistency and construct validity. - Short and easy for patients to complete.	- Dichotomous: unable to identify/no cut-off for pre-frail. - Not covering all 3 domains of interest. - Low predictive power [Daniels 2012]. - Not validated in Italian population.
TFI	- Available in English and Dutch. - High internal consistency and construct validity.	- Dichotomous: unable to identify/no cut-off for pre-frail. - Not covering all 3 domains of interest. - Not validated in Italian population.
IM-E-SA	- Available in English, Dutch and Italian. - Good internal consistency. - Used to detect older adults with complex care needs.	- Not covering all 3 domains of interest. - Only validated in a Dutch population.
SPQ	- Short and easy for patients to complete. - High sensitivity compared with the TFI & GFI [Daniels].	- Dichotomous: unable to identify/no cut-off for pre-frail. - Low internal consistency and construct validity. - Low specificity for the development of disability. - Not covering all 3 domains of interest. - Not validated in Dutch or Italian population.
EARLI	- Short and easy for patients to complete.	- Dichotomous: unable to identify/no cut-off for pre-frail. - Not covering all 3 domains of interest. - Not validated in Dutch or Italian population.
SHARE-FI	- Divides patients into non-frail, pre-frail and frail. - Software is free to use (online calculator). - Developed based upon EU population. - Based upon Fried's original frailty criteria.	- Not covering all 3 domains of interest. - Requires specialized equipment e.g. hand-held dynamometer.
FI	- Divides patients into non-frail, pre-frail and frail. - Utilizes existing databases. - Focuses on accumulation of deficits. - Developed using 70 deficits from the clinical examination, therefore thorough.	- Not covering all 3 domains of interest. - Requires large numbers, with relatively high "deficit" prevalence. - Requires "center specific" software and access to a database. - Cost of software
CFS	- Divides patients into non-frail, pre-frail and frail. - Global measure, providing an overview. -	- Not covering all 3 domains of interest. - Not validated in Dutch or Italian population. - Scored by a trained rater only.
CHS (Fried)	- Divides patients into non-frail, pre-frail and frail. - Well-established criteria that provided the basis for the initial definition of frailty. - Validated in patients >65 years of age.	- Not covering all 3 domains of interest. - A clinical assessment is required. - Requires specialized equipment e.g. Jamar hand-held dynamometer.

Table 7 - Individual components of the different frailty screening instruments reviewed.

Name	Reference	Rated by	Outcome	Scoring
Cardiovascular Health Study Index (CHS) or Fried criteria	Fried et al. 2001	Observer	Robust, pre-frail, frail	A combination of three or more of the following: - unintentional weight loss - self-reported exhaustion - weakness (grip strength) - slow walking speed - low physical activity
Study of Osteoporotic Fractures Index (SOF)	Ensrud et al. 2008	Observer		A combination of two or more of the following: - weight loss (five percent in last the year) - physical weakness (the inability to rise from a chair five times without use of arms) - lack of energy (answering no to the question "do you feel full of energy?"
Survey of Health, Ageing and Retirement in Europe-Frailty Instrument (SHARE FI)	Romero-Ortuno et al. 2010	Observer	Non-frail, pre-frail, frail	Five variables are used to predict frailty: - Exhaustion - loss of appetite - weakness (determined by grip strength) - walking difficulties - low physical activity
Frailty Index (FI)	Song 2010	Observer	Non-frail, pre-frail, frail	The proportion of identified deficits in a list of 36 predefined variables
FRAIL scale		Observer		Five measures are used to predict frailty: - Fatigue - Resistance - Ambulation - Illnesses - Loss of weight
The Emergency Admission Risk Likelihood Index (EARLI)	Lyn et al 2007	Self-assessed	Probability of emergency admission	Six item survey about: - Heart problems - Leg ulcers - Mobility - Memory - Recent hospitalization - General health status
Geriatric Postal Screening Survey (GPSS)	Alessi et al 2003	Self-assessed	Probability of hospitalization or institutionalization at one year	
Tilburg Frailty Indicator (TFI)	Gobbens et al 2010	Self-assessed	Frailty	25 yes or no questions on determinants or components of frailty

(Continuation of

Table 7)

Name	Reference	Rated by	Outcome	Scoring
Groningen Frailty Indicator (GFI)		Self-assessed	Non-frail, frail	15 yes or no questions covering four domains: - physical - cognitive - social - psychological
Sherbrooke Postal Questionnaire (SPQ)	Herbert et al	Self-assessed	Risk of functional decline	6 yes or no questions about: - Living alone - > 3 medications a day - Use of cane, walker or wheelchair - Vision - Hearing - Problems with memory
Vulnerable Elders Survey (VES)	Saliba et al	Self-assessed	Risk of functional decline or death	13 items about: - Age - Health status - Difficulty with physical activities - Limitations in daily activities

Figure 1 - Groningen Frailty Indicator scale including its physical, cognitive, social and psychological components.

Physical components

1	Shopping	Yes	No
2	Walking around outside (around the house or the neighbors)	Yes	No
3	Dressing and undressing	Yes	No
4	Going to the toilet	Yes	No
5	What mark do you give yourself for physical fitness? (scale 0 – 10)		
6	Do you experience problems in daily life because poor vision?	Yes	No
7	Do you experience problems in daily life because of being hard of hearing?	Yes	No
8	During the past 6 months have your lost a lot of weight unwillingly? (3 kg in 1 month of 6 kg in 2 months)	Yes	No
9	Do you take 4 of more different types of medicine?	Yes	No

Cognitive component

10	Do you have any complaints about your memory	No	Sometimes	Yes

Social component

11	If you are at work, with your family, or at church do you believe that you are part of the social network?	Never	Sometimes	Often	All the time
12	Do other people pay attention to you?	Never	Sometimes	Often	All the time
13	Will other people help you if you are in need?	Never	Sometimes	Often	All the time

Psychological component

14	In the past 4 weeks did you feel downhearted or sad?	Never	Seldom	Sometimes	Often	Very often	All the time
15	In the past 4 weeks did you feel calm and relaxed?	Never	Sometimes	Sometimes	Often	Very often	All the time

5.2.2 Proposed Frailty instruments for PERSSILAA

There are a wide variety of possible screening tools (see previous overview). A combined screening with both a subjective (self-rated, e.g., a postal questionnaire) and objective (rater-observed) screen has been suggested previously (Drubbel et al). We will follow this suggestion and introduce a two-step screening process.

Groningen Frailty Indicator (GFI)

Based upon the state of the art literature review undertaken, the Groningen Frailty Indicator (GFI), a self-rated screen was selected as part of the initial screen for PERSSILAA (see Figure 4). The GFI consists of 15 yes-no questions (score range from zero to fifteen), under four domains: physical, cognitive, social and psychological (Steverink et al). A score of 4 or more is regarded as moderate to severely frail (Steverink et al). The GFI is dichotomous dividing patients into clearly frail versus less frail or robust. The GFI has moderate positive correlation with the observer rated Frailty Index (Drubbel et al). Authors have suggested using the GFI as part of a potential two-step frailty screening process in primary care (Drubbel et al). The GFI was selected as the initial frailty screen as it is widely used in the Netherlands, available in the three key languages of the study: English, Dutch and Italian, it

has high internal consistency and construct validity and it is short and easy for patients to complete.

INTERMED

The INTERMED (Peters et al), (Wild et al) was also chosen as part one of the frailty screen as it provides additional, complementary information on quality of life, health care usage and the biological symptoms of chronic disease (see Appendix 1). The INTERMED is a self-rated questionnaire consisting of 20 questions, which cover biological, psychological, social factors and the extent of recent healthcare usage. Conveniently available in English, Dutch and Italian, the INTERMED has good internal consistency and is used to detect older adults with complex care needs. It covers domains not covered by the GFI.

The INTERMED is scored as follows:

- Frail: INTERMED-E-SA ≥15.
- Pre-frail: <15
- Robust: <15

Fried Frailty criteria

The second round of screening will be face-to-face. The chosen instrument for second step screening is the Fried criteria. Here, the participants will be assessed clinically and have a brief targeted history and examination. The Fried criteria will be applied to separate individuals into pre-frail and frail. The Fried criteria, also known as the Cardiovascular Health Study (CHS) Index (Fried et al 2001), defines the frailty phenotype as a combination of three or more of the following:

Fried Frailty criteria,

1. Weight loss (>5% in last year)
2. Exhaustion
3. Weakness (decreased grip strength)
4. Slow walking speed (>6 to 7 seconds for 15 feet)
5. Decreased physical activity (males <383 kilocalories); females <270 kilocalories)

The Fried criteria were selected as they are the most well-established criteria for clinical frailty, they are easy to assess and are widely validated in patients >65 years of age, PERSSILAAs target audience. They additionally provide the basis for the initial definition of frailty established over a decade ago. They also clearly divide patients into non-frail, pre-frail and frail.

In practice each of the Fried frailty criteria are defined as follows;

1. The **weight loss** criterion was fulfilled by reporting a “Diminution in desire for food” in response to the question: “What has your appetite been like?” or, in the case of a non-specific or uncodable response to this question, by responding “Less” to the question: “So, have you been eating more or less than usual?”. The presence of the criterion was coded as 1 and its absence as 0.
2. **Exhaustion** was identified as a positive response to the question: “In the last month, have you had too little energy to do the things you wanted to do?”. A positive answer (*Yes*) was re-coded as 1, and *No* was re-coded as 0.

3. **Weakness** was assessed by handgrip strength (Kg) using a dynamometer. Two consecutive measurements were taken from the left and right hands. The highest of the four was selected. This variable was kept continuous.
4. **Slow walking speed** was defined as it taking the patient more than 6 to 7 seconds to walk 15 feet (three meters approx.)
5. **Decreased physical activity** is defined by a reduction in energy expended. For males <383 kilocalories); females <270 kilocalories). This criterion can also be assessed by the question: "How often do you engage in activities that require a low or moderate level of energy such as gardening, cleaning the car, or doing a walk?". This variable was kept ordinal: 1 = "More than once a week"; 2 = "Once a week"; 3 = One to three times a month" and 4 = "Hardly ever or never".

Pre-frail individuals, the target population for PERSSILAA are those who score of one or two from the five.

Thus, we will perform an initial survey to screen our target population for general frailty, using the GFI and the INTERMED for elderly Self-Assessment. Respondents will also complete short screening instruments to identify frailty risk factors related to nutrition, cognition and physical function. Via this screening, we will identify those whose status is likely to be too complex to be improved by the PERSSILAA services. These include those already receiving a lot of (complex) care, or those that are in need of it. These will not be triaged to the PERSSILAA services, but will instead be advised to contact an appropriate care professional if applicable. We will then identify those that are robust, those older people who are independent and in no need of medical intervention. They will be given access to the PERSSILAA self-management services to maintain this level, and to serve as a normal control group in the validation study (WP5). Finally, there are those who are pre-frail or mildly frail. These will be invited for the second round of screening. Please note that, in this screening stage, all questionnaires will also be offered in an online version, next to a paper-and-pencil version. With the online version, if someone is still identified as overly complex or mildly frail, further screenings for individual domains will not be offered, as they will add little value. Screening instruments and the rationale for their selection are presented in Chapters 6-8 below.

6 Screening Tools for Physical Functioning

6.1 Overview of the existing physical screening instruments

The objective of the physical screening of PERSSILAA is to identify participants who are limited in their ADL tasks and mobility levels and who might benefit from an exercise program that focusses on physical functioning.

Physical functioning

The decline of physical function of older adults, associated with loss of independent living status, is a major public health concern. Change in physical functioning is a primary determinant of quality of life in old age; even relatively modest declines in functioning capabilities are associated with loss of independence, increased caregiver burden, and greater financial expenditures (Fried et al 2003), (Reuben et al). Physical functioning can be conceptualized (and studied) across a hierarchy of increasing complexity, from a focus on specific physical movements, such as lifting and walking, to a focus on more integrated activities such as the ability to maintain occupational and social roles (Guralnik et al). As such, physical functioning concerns both [1] the ability to perform physical and daily activities, also expressed as mobility (walking, climbing stairs) and [2] Activities of Daily Living (ADL) (bathing, dressing, eating).

How to measure physical functioning

Physical functioning can be assessed by various instruments and methods. Roughly speaking, the methods are self-reported (questionnaires) or objective measurements (performance based tests).

Self-Report Measures of Physical Functioning

Over the last several decades, numerous tools have been developed to assess patients' abilities to perform activities of daily living and mobility impairment by means of self-report (Guralnik et al), (Kovar et al). There are more than 100 published basic ADL or mobility scales, with considerable variations in the number of questions, item content, and scoring method. In case of self-reports, the participant is asked to report on their functional abilities. As such, self-reports are considered subjective in that it requires a respondent to either endorse or deny functioning difficulties based on his/her own perceptions of personal "difficulty" in performing the activity in question. Commonly used self-report measures generally collect information in terms of either dichotomous as yes/no responses (do/do not have difficulty), or allow for responses along a more graded continuum of reported severity ranging from little difficulty to great difficulty. Research on physical functioning in old age was primarily based on such self-reported status measures as a means of measuring functioning difficulties. Examples of some of the instruments used to measure disability include Katz ADL, The Barthel Index, and The Health Assessment Questionnaire (HAQ) Disability Scale. A comparison of the different screens is presented in Table 8.

Table 8 - Selected overview of the instruments to measure Instrumental Activities of Daily Living (IADL) and physical performance by means of self-report. NA: Not Available

Instrument	Assessment	Score
KATZ index/ ADL Index	Ability to perform: bathing, eating, dressing, continence, transfers to toilets and locomotion	0 independent-6 dependent
(modified) Barthel index	Feeding, urinary and faecal continence, personal toilet, dressing, toilet use, transferring, walking outdoors, climbing stairs and bathing	1 dependent- 20 independent
Lawton index/ Instrumental ADL index	Ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for medication and ability to handle finances	0 dependent- 8 independent
SMS Dependency scales	SMS independency scale: 20 questions relating to orientation, communication, mobility, transfers, ADL continence, catheter use, and decubitus.	NA
Functional independence measure	Measures the level of the patient's disability and indicates how much assistance is needed for the individual to carry out activities of daily living.	18 dependent- 126 independent
Walking impairment questionnaire	Walking distance, walking speed, climbing stairs	0-100
Physical activity scale	Questionnaire about walking ¼ mile, walking up 10 steps, crouching/kneeling, lifting/ carrying 10 lbs.	NA
Mobility	Walking to a table, walking inside the house, walking a block, walking uphill or upstairs, running a short distance	NA
Health assessment questionnaire	Dressing, rising, eating, walking, hygiene, reach, grip, activities	0 independent-60 dependent
Physical functioning scale SF36	Vigorous activities, moderate activities, lifting or carrying groceries, climbing several flights of stairs, bending, kneeling or stooping, walking more than one mile, walking several blocks	0 limited-100 not limited

Performance Based Measures of Physical Functioning

Although self-report measures are valuable for identifying older adults at the moderately to severely disabled end of the spectrum, performance-based measures are considered more objective. In performance-based measures, a respondent attempts certain tasks or movements while ability is objectively assessed by a test administrator. These objective assessments are generally measured along a continuum in terms of speed, repetition, or capacity and normally are linked with a specific ability necessary for functioning in old age. A large number of physical performance measures, either individual tests or batteries of tests, have been developed and many of them assess different aspects of functional limitation. A recent review of Freiberger et al (2012) investigated performance-based physical function in older community-dwelling persons. Their aim was to assess instruments with an overall score

related to functional status and/or physical performance on content and psychometric properties The included instruments were Continuous Scale Physical Performance (CS-PFP) with two modifications, MacArthur battery, Modified Timed Movement Battery (Mod TMB), mobility-related limitation index (MOBLI Index), Physical Capacity Evaluation (PCE) with one modification, Performance-Oriented Mobility Assessment (POMA) with one modification, Performance-based Physical Function Test (PPF), Physical Performance Test (PPT) with five modifications, Shinkai Summary Performance Score (SSPS), Short Physical Performance Battery (SPPB) with three modifications, Task Modification Scale (TMS) and Upper Extremity Summary Performance Score (UESPS) with one modification. The SPPB can be recommended most highly in terms of validity, reliability and responsiveness, followed by the PPT.

6.2 Proposal for PERSSILAA

The physical screening proposed in PERSSILAA is aimed to identify participants who are limited in their ADL tasks and mobility levels and who might benefit from an exercise program that focusses on physical functioning. This can be done using self-report or by means of performance tests. Doing performance tasks on every older person is very time-consuming and as such probably not useful on a large scale. In addition intensive screening is only necessary when specific exercise programs need to be composed and as such not necessary for every elderly. Therefore, we propose a two-step screening. In step one instruments that can be administered easily by the elderly themselves or their informal carer and can is able identify those who are physically impaired or not. In step two physical functioning will be assessed in more detail. In more detail

1. First screening: This will identify participants who are physical impaired or physically robust. For the physically robust participants, no more detailed (second) screening is needed, but they can for instance get access to a standardized self-management program to maintain their condition.
2. Second screening: For the participants who are defined as physically impaired during the first screening, a second more detailed screening will be performed to identify in more detail on what physical domain the participant has problems, by means of physical performance tests. This information can subsequently be used to design that person to an individual tailored exercise program. The performance tests should identify those joints and muscle groups that are in need of improvement and appropriate exercises for the physical training program can be selected (see Figure 5).

This two-step screening procedure will eventually lead to two different types of physical training programs (see Figure 5), being a:

1. **Standardized** self-management exercise program for physically fit older adults including information about physical fitness and health promotion
2. **Professionally supported and personalized** program for physically impaired older adults which can be performed in the home situation of the participant or at location and optionally in a group.

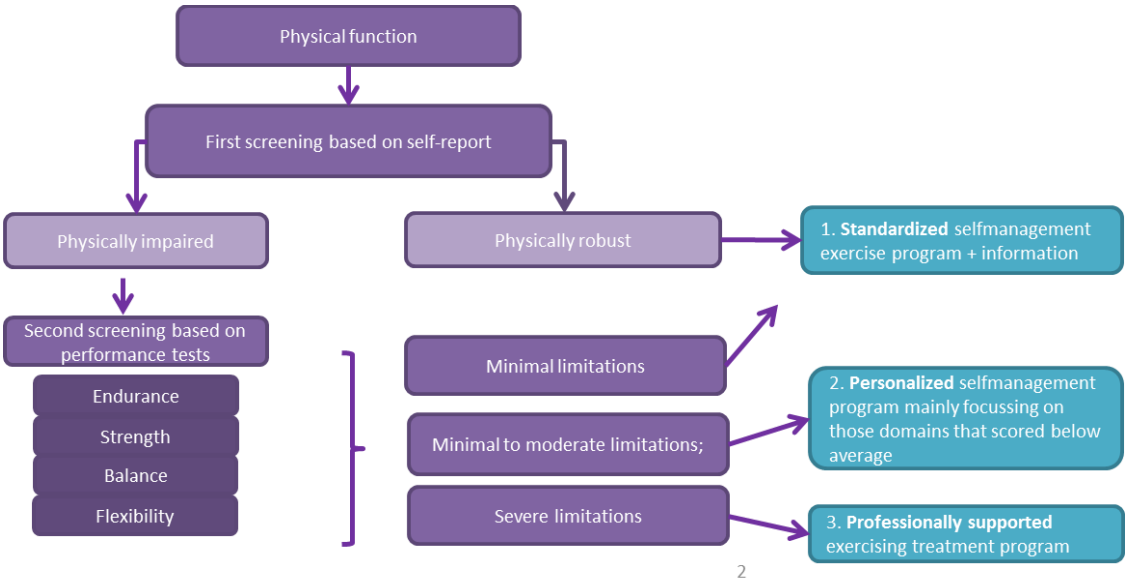


Figure 2 - Global overview of the physical screening procedure of PERSSILAA.

6.2.1 First screening

This first screening step needs to be short and easy to fill in (online or offline) and based on the outcome it can be identified whether that person is physically fit or not. Unfortunately, there is no gold standard for measuring physical function; therefore we have looked at instruments that meet the following requirements:

1. It should be reliable and valid for the older population
2. It should be suitable for the older population
3. Easy to administer by the elderly themselves
4. There have to be reference values about the outcome of the score at the questionnaire for the older population
5. It should have been used in an European setting and/or fit the use in the country of admission

Starting from these requirements we identified the two most widely used and reliable and valid instruments suitable for the older population that can answer our question who might be physically impaired both in terms of mobility impairment and in terms of ADL disability.

ADL disability

The Katz index has emerged as an especially useful tool for assessing ADL disability in older adults. Because of its predictive value, the Katz index is often used to determine eligibility for assistance and benefits and by researchers studying older adults. The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the client's ability to perform activities of daily living independently (Shelkey et al 2012). It is easy to use also been used widely in the Netherlands in line with "Nationaal Programma Ouderenzorg".

Mobility Impairment

A questionnaire that meets the criteria for this aspect of physical functioning is the physical functioning scale of the SF-36. SF-36 PF scores are related to physical performance across a

range of tests (Syddall et al 2009). The physical functioning (PF) domain of the established and widely used Short Form-36 (SF-36) questionnaire asks about limitations on ten mobility activities.

The Physical functioning scale of the SF-36 (also mentioned in literature as MOS or RAND 36) focusses on mobility impairment and the KATZ index on activities of daily living, both important aspects of physical functioning, they might well supplement one another for physical screening purposes.

In summary, we propose to use the KATZ index- ADL and the SF-36 for the physical screening of PERSSILAA (see Table 9 below).

Table 9 - Criteria used for defining first physical screening for PERSSILAA.

	KATZ-ADL	**SF-36**
Reliable and valid	+ Katz et al 2003	+ Bohannon et al 2010
Suitable for older population	+	+
Easy to administer	+	+
Cut-points available	+ Shelkey et al 2012	+ Van der Zee 1996
European use	+	+

KATZ index- ADL

The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the client's ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The Index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored yes/no for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.
The instrument is most effectively used among older adults in a variety of care settings. The tool is used extensively as a flag signalling functional capabilities of older adults in clinical and home environments.

Do you need help with:

- Bathing
- Dressing
- Toileting
- Continence
- Transfer
- Feeding

SF-36

Self-reported physical functioning is assessed using the 10-item physical functioning (PF) subscale of the SF- 36-item Health Survey (RAND-36) (van der Zee et al 1993). The physical functioning subscale is a reliable and valid scale for measuring limitations in daily activities due to health problems (Cronbach's $\alpha = 0.92$). It measures limitations in vigorous activities (PF1), moderate activities (PF2), carrying groceries (PF3), climbing several stairs (PF4), climbing one stair (PF5), bending/kneeling (PF6), walking more than one kilometre (PF7), walking half a kilometre (PF8), walking 100 metres (PF9) and self-care (PF10). The respondent reports to what extent he feels limited in a particular activity (*limited a lot / limited a little / not limited at all).* Raw scores are transformed into index scores ranging from 0 to 100. After transformation, lower scores on the physical functioning subscale indicate more limitations in activities of daily living.

Does your health now limit you in the following activities? If so, how much?

- Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
- Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf
- Lifting or carrying groceries
- Climbing several flights of stairs
- Bending, kneeling or stooping
- Walking more than one mile
- Walking several blocks
- Walking one block
- Bathing or dressing yourself

Cut-off points

Participants are classified as limited in physical functioning if they score below a cut-off score of 61 (pooled mean score in a general older Dutch population; 63–77 years: mean 64.8, 78 year or older: mean 57.3) (van der Zee et al) or have a KATZ ADL score below 5 (Shelkey et al).

6.2.2 Second screening

If participants are defined as physically impaired on one of the two domains measured in the first screening (ADL, mobility), a more detailed screening will be performed to identify in more detail on what physical domain the participant has problems. Being able to perform everyday activities (e.g. personal care, shopping, housework) requires the ability to perform functional movements, such as walking, stair climbing and standing up; and that these functional movements, in turn, are dependent on having sufficient physiologic reserve (i.e. strength, endurance, flexibility, balance). As such, the second screening will be based on performance tests, measuring strength, endurance, flexibility and balance as they are important for older adults to accomplish everyday tasks. Assessing these components of fitness can detect weaknesses which can be treated before causing serious functional limitations. Therefore we define performance test that address these specific domains in order to define exercises and personalized treatment for the elderly in the domain where it is most needed. For the second part of the physical screening different short standardized validated

tests will be used, defining different physical components of frailty of the elderly being: aerobic endurance, strength, flexibility and balance (see Figure 2).
To date, several different measurement instruments for overall physical function are frequently used in practice. However, for the use of PERSSILAA, a few things have to be taken into account when deciding which performance test to use for the specific domains. In this decision, the performance tests should meet the following criteria:

1. Low technological demand, meaning that they are portable, inexpensive, and can be used in diverse settings in the community, even at home with help of an informal caregiver;
2. Suitable for an older population; being safe and easy;
3. Reliable and valid for the older population;
4. Criterion references for different age groups to define weaknesses in the different domains.

This results in the following performance tests for the second part of the screening, meeting the criteria as set above.

Balance
The Timed up and go test assesses agility and dynamic balance, attributes that are needed for a number of functions such as getting up. The test involves getting up from a seated position and walking as quickly as possible around a cone (or similar marker) that is 8 feet (2.44 meter) away and returning to the seated position (Blankevoort et al),(Podsiadlo et al).

Strength
Lower body strength is important aspect of physical fitness in older adults because of its role in common everyday activities such as walking, maintaining balance etc. The chair-stand test is a reliable and valid test to measure lower body strength. The test involves counting the number of times, within a 30 sec period, that a person can come to a full stand from a seated position with arms folded across the chest (Jones et al).

Flexibility
Flexibility is an important but often neglected component of physical fitness. Flexibility is important for maintaining good posture en reducing the risk of injuries and back problems. It is also critical for tasks of daily living, such as tying shoes, kneeling down to pick up objects from the floor and combing hair. Therefore, a performance test that measures flexibility is included, being the chair sit and reach test. The chair sit and reach test assesses hamstring flexibility, which is important for good posture and for mobility tasks, such as walking, stair climbing and for getting in and out of the car. The test involves sitting at the front edge of a stable chair, with one leg extended and the other foot flat on the floor. With hands on top of each other and arms outstretched, the object is to reach as far forward as possible toward the toes. The score is defined by the number of inches (centimetres), either plus or minus, between the tips of the middle fingers and the toes (Jones et al).

Endurance
The two-minute step test is a reliable and valid test as an alternate measure of aerobic endurance when space limitations prohibit use of the 6-minute walk test. The two-minute step protocol involves determining the number of times in two minutes that a person can step in place raising the knees to a height halfway between the patella and iliac crest.

Cut points

For each of the performance tests, cut-off points are available adjusted according to age and gender (see Table 10).

Table 10 - Normal range scores for men and women.

Variable	**Gender**						
Age Range		**60-64**	**65-69**	**70-74**	**75-79**	**80-84**	**85-89**
Chair stand test	Men	14-19	12-18	12-17	11-17	10-15	8-14
	Women	12-17	11-16	10-15	10-15	9-14	8-13
2-minute step test	Men	87-115	86-116	80-110	73-109	71-103	59-91
	Women	75-107	73-107	68-101	68-100	60-91	55-85
Chair sit and reach test	Men	-2.5-+4.0	-3.0-+3.0	-3.0-+3.0	-4.0-+2.0	-5.5-+1.5	-5.5-+1.5
	Women	-0.5-+5.0	-0.5-+4.5	-1.0-+4.0	-1.5-+3.5	-2.0-+3.0	-2.5-+2.5
Timed up and go	Men	5.6-3.8	5.9-4.3	6.2-4.4	7.2-4.6	7.6-5.2	8.9-5.5
	Women	6.0-4.4	6.4-4.8	7.1-4.9	7.4-5.2	8.7-5.7	9.6-6.2

7 Screening tools for cognition

Definitions of Mild Cognitive Impairment (MCI) and Dementia

Mild cognitive impairment (MCI) represents a heterogeneous group of disorders of memory impairment (Peterson et al). Individuals with MCI have variable, subtle, cognitive changes. Although many go on to develop dementia, the rate of progression varies considerably. The annual conversion rate from MCI to dementia is estimated at between 5 and 10% (Mitchell, Shiri-Feshi et al). The reason for this is due to variability in the definitions used (Fisk et al) and in the diagnostic methods employed. Dementia will be defined according to Diagnostic and Statistical Manual of Mental Disorders, (4th edition) criteria (APA). There are several challenges with respect to cognitive screening and the selection of an appropriate cognitive screening test. Initial literature search revealed five key questions that directed our selection:

1. What type of cognitive screening is required?

The U.S. Preventive Services Task Force recently reviewed the evidence base for cognitive screening (Lin et al) among unselected community-dwelling older adults in primary care, concluding that there is insufficient evidence to recommend any single short cognitive screen. Few short tests have been widely validated in primary care and questions remain regarding the ethical (Boustani et al 2013) and clinical benefits of unselected screening (Lin et al).

2. Why screen?

To date, there is a lack of empirical evidence supporting current expert consensus guidelines extolling the benefits of early detection of cognitive impairment (mild cognitive impairment or early dementia). Screening for cognitive impairment doesn't yet meet Wilson's Criteria, recognized as the gold standard for the utility of any screening initiative. This is predominantly due unlike screening for other conditions, the benefits of screening for cognitive impairment lies in health promotion i.e. planning for the future. This is difficult to measure and may explain the paucity of evidence to date with respect to unselected screening. There is however, growing evidence that screening for cognitive impairment among selected samples may benefit patients, particularly at risk populations including those with multiple co-morbidities. This leads on to the third key question.

3. Who should be screened?

In addition to screening symptomatic patients, the effects of targeting high-risk groups with the right cognitive screen, for example those with Parkinson's disease, require examination. In addition, patient populations are heterogeneous with different subgroups requiring different cut-off scores adjusted for age and education. The effect of developing and validating these among large populations of patients with different dementia subtypes is also required.

4. When should cognitive screening take place?

Cognitive impairment is a heterogeneous disorder and presents in a heterogeneous fashion. In this sense one single screening policy is unlikely to be successful. Little evidence is available comparing triggers for screening in the community (Lin et al).

5. Where should screening take place?

Although there is a paucity of evidence for screening in primary care, research from memory clinics suggests that primary care offers superior post-diagnostic management (Meeuwsen et al) over secondary care.

7.1 Overview of the existing cognitive screenings instruments

Multiple cognitive screening tests are available, each with different psychometric properties. Cognitive screening tests can be either direct neuropsychological observer rated instruments. Observer rated tests are informant guided questionnaires or interviews. There is evidence to support that the addition of an observer rated test improves the diagnostic accuracy of directly administered neuropsychological screen (Roalf et al). Observer-rated scales must however, be interpreted with caution as ageing caregivers may be developing cognitive difficulties themselves or may know the subject too well or insufficiently to be objective (Nieuwenhuis-Mark). As the goal of PERSSILAA is to allow patients to self-administer cognitive screens, we present a selection of the most commonly used direct neuropsychological and observer rated instruments, which we propose to use to validate PERSSILAAs' self-administered screening process (step one) in the second step of screening, the "face to face" assessment.

Direct neuropsychological cognitive instruments

The standardized Mini-Mental State Examination (SMMSE)

The Mini-Mental State Examination (MMSE) [Folstein] is the most widely used short cognitive screening text. The Standardised Mini-Mental State Examination (SMMSE) is a standardised form of the MMSE with improved inter-rater reliability that uses explicit administration and scoring guidelines (Molloy 1991),(Molloy 1997). Like the MMSE it is scored from 30 points. The MMSE and SMMSE have a limited role in identifying MCI (Mitchell, Shiri-Feshki), lacking sufficient sensitivity to differentiate between NC and MCI, in particular, where individuals have higher levels of academic achievement (Crum et al).

The Montreal Cognitive Assessment (MoCA)

The Montreal Cognitive Assessment (MoCA) is a short cognitive screening test with high sensitivity for detecting CI, over and above the MMSE (Nasradeine et al). It has seven subtests covering five cognitive domains; memory, language, visuospatial, attention and cognitive control, scored out of 30 points (Nasradeine et al). Although the MoCA is increasingly accepted as one of the short cognitive screens of choice, its use presents some challenges. It is long, taking at least 10 minutes to complete (Nasradeine et al) and is considered by some to be too difficult to use in those with significant CI (O'Caoimh, Molloy W 2013). No age or education specific cut-offs are available for those with CI and the utility of its recommended cut-off score (<26) has been questioned (Luis et al). The specificity of the MoCA at a cut-off score of <26 is low, with studies demonstrating specificities between 35% (Luis et al) and 50% (Smith et al). Recently, it has been suggested that lowering its cut-off will improve its specificity without adversely affecting sensitivity (McLennan et al), (Freitas et al). However, uncertainty remains as to which cut-off is most appropriate and in which setting. In addition, the MoCA subtest scores have also been criticized for having unacceptably poor levels of accuracy when predicting impairment in their respective cognitive domains (Moafmashhadi et al).

The General Practitioner Assessment of Cognition (GPCOG)

The General Practitioner Assessment of Cognition (GPCOG), designed specifically for use in general practice, is short (5-6 mins) and acceptable to patients and physicians alike (Brodaty 2002). It has however, been criticised for having age and educational bias (Cullen et al), (Brodaty 2004).

The Quick Mild Cognitive Impairment (Qmci) screen

The Quick Mild Cognitive Impairment (Q*mci*) screen is described in detail in Section 7.2.

Observer rated cognitive instruments

The Informant Questionnaire-short form (IQCODE)

The Informant Questionnaire-short form (IQCODE) (Jorm 1994) is a widely used observer rated instrument usually scored by families or close contacts. It is limited by its length, albeit shorter than the original version, and its awkward scoring. It not useful in detecting decline in cognition over time [Eramudugolla].

The AD8 Dementia Screening Interview

The AD8 (Gavin 2005), a more recent observer rated cognitive instrument (See Appendix 1). An informant answers eight questions on whether there has been a recent change (over several years) directly attributable to memory loss in a variety of daily tasks. Answers can be yes (a change), no or don't know. A score of one point is given for every score answered yes. A score of two or greater is suggestive of cognitive impairment (sensitivity of 84% and specificity of 80%). The test can also be administered to or self-administered by the patient directly, although an informant is preferable.

Table 11 - Comparison of different cognitive screening instruments.

Classification	Instrument	Advantages	Disadvantages	Timing (mins)	Reference
Observer Rated	**IQCODE**	Short form available Comprehensive	Lengthy Difficult to score	10	Jorm et al
	AD8	Short Can be self-administered	Less comprehensive than IQCODE	2	Gavin et al
Neuro-psychological Instrument	**MMSE**	Widely used translated & validated	Low sensitivity in those with high education	10	Folstein
	MoCA	Widely used translated & validated. High sensitivity	Low specificity in older adults with low education	10-12	Nasradeine et al
	Q*mci*	High sensitivity & specificity in older adults. Short admin time Translated into English, Dutch & Italian	Not widely validated	4.24	O'Caoimh et al
	GPCOG	Combines observer & neuropsychological components	Age & educational bias	4-6	Brodaty et al
	QMC	Can be self-administered	Not widely validated	2.5	O'Caoimh et al
	TYM	Can be self-administered	Requires rater supervision		Brown et al
	ADAS-cog	Gold standard in RCT studies	Lengthy administration time	45	Rosen et al

7.2 Description of the Cognitive Screening Instruments

The Quick Mild Cognitive Impairment screen (Q*mci*)

The Quick Mild Cognitive Impairment screen (Q*mci*) is a short screening test for cognitive impairment, developed as a rapid, valid and reliable tool for the early detection and differential diagnosis of mild cognitive impairment (MCI) and dementia (O'Caoimh et al 2012). The Q*mci* has six subtests, covering five domains: orientation, registration, clock drawing, delayed recall, verbal fluency (naming animals) and logical memory (LM), an immediate verbal recall of a short story. It is scored out of 100 points and has a median administration time of 4.24 minutes (O'Caoimh et al 2013). The Q*mci* was derived from the ABCS 135 by reweighting its subtests and adding LM (O'Caoimh et al 2012). It has superior sensitivity and specificity for differentiating MCI from normal cognition and dementia compared to the standardized MMSE and the AB Cognitive screen 135 (O'Caoimh et al 2012). It also correlates with the standardized Alzheimer`s Disease Assessment Scale-cognitive section (ADAS-cog), Clinical Dementia Rating (CDR) scale and the Lawton-Brody activities of daily living scale (O'Caoimh et al 2014).

Cut-off scores for the Q*mci*

The recommended cut-off scores are <60, for cognitive impairment and <50 for dementia [O'Caoimh et al, unpublished work]. Age and educational cut-offs are also available, with a score of less than 54 points for CI for those >75 years of age with < 12 years education, 56 for those >75 with ≥ 12 years education, 67 for those ≤ 75 years and ≥ 12 years education, and 57 for those ≤ 75 with < 12 years education (See Figure 6). Alternative validated versions are also available (Cunje et al).

The Quick Memory Check (QMC)

The Quick Memory Check (QMC) is based upon the Q*mci* screen. Previous analyses of the Q*mci* subtests revealed that verbal fluency (VF) and LM best differentiated MCI from normal cognition, while orientation best differentiated MCI from dementia (O'Caoimh et al 2013). Based upon this analysis, the Q*mci* was shortened and reweighted to produce the QMC, see Appendix 1. Orientation was increased to 15 points (from 10 points), VF (for animals as initial piloting found that animals were the easiest to score) from 20 to 40 points and LM from 30 to 45 points. The QMC was designed to be completed in three minutes, 30 seconds for the caregiver report and two and half minutes for the caregiver assessment (one minute for the orientation and VF subtests each and 30 seconds for LM). The median administration time is 2.5 mins.

Cut-off scores for the QMC

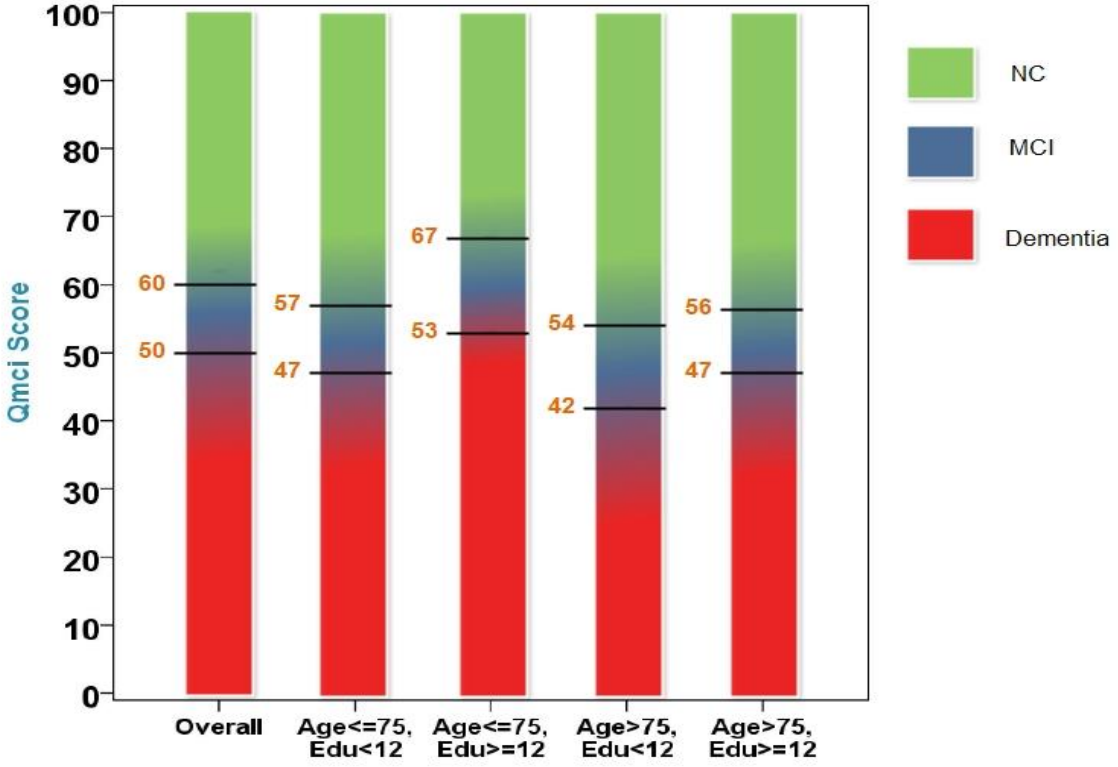
At a cut-off of <50 the QMC had a sensitivity of 85% and specificity of 80% for diagnosing CI. The majority of raters (82%) were happy to score the test again.

Thus, the QMC, administered by untrained raters in an informal setting, compares favourably to established cognitive screens administered by trained raters.

Table 12 - Comparison of the Quick Mild Cognitive Impairment (Qmci) Screen and Quick Memory Check (QMC).

Qmci	Score	QMC	Score
Orientation	10	**Orientation**	15
Registration	5	**Verbal fluency**	40
Clock drawing	15	**Logical Memory**	45
Delayed recall	20		
Verbal fluency	20		
Logical Memory	30		
Total	100	Total	100

Figure 3 - Age and educational cut-off scores for the Quick Mild Cognitive Impairment (Q*mci*) screen (image copyrighted).



Justification of the Selection of Cognitive Screening Instruments

The Q*mci*

Although multiple short cognitive screens are in use (Cullen et al), we selected the Q*mci* and the QMC, which is itself based upon the Q*mci*, as the screening instruments for PERSSILAA. The most widely used short cognitive screening instrument [Shulman] is the mini-Mental State Examination (Folstein et al). There are however several well established challenges with using the MMSE in clinical practice, particularly in screening for MCI and early dementia (Mitchell et al), especially among those with high educational attainment (Crum et al). The Q*mci* has demonstrated superior accuracy over the MMSE both in identifying MCI and mild dementia (O'Caoimh et al). More recently, the Montreal Cognitive Assessment (MoCA) has been developed and widely validated in the detection of MCI and early dementia (Nasradeine et al). Although the MoCA has been compared with the MMSE, in multiple clinical settings, it has rarely been compared to short screens designed specifically to detect MCI. Comparison of the Q*mci* with the MoCA showed that the Q*mci* was more accurate with shorter administration times [O'Caoimh et al unpublished work]. Specifically the Q*mci* was more accurate than the MoCA in differentiating MCI from those with normal cognition, area under the curve (AUC) of 0.82 versus 0.74. It also had superior accuracy in differentiating MCI from dementia, AUC of 0.96 versus 0.91. At the recommended cut-off scores for each test, the Q*mci* (<60) had greater sensitivity (88%) and specificity (88%) for cognitive impairment, compared with 96% and 41% respectively for the MoCA (<26). Median administration times were 4.52 minutes for the Q*mci* compared with 9.52 minutes for the MoCA.

Self-diagnosis using internet-based search engines is increasingly commonplace. With the growing use and availability of the internet, particularly on mobile devices, there has been an increase in the propagation of internet-based self-administered tests for dementia (Robillard et al). There are several proposed benefits to "home" self-administered assessment. The setting is familiar to patients potentially reducing the anxiety associated with clinic assessments. Time is limited in clinical practice and performance fluctuates over time. Home-administration may minimize this, allowing for more frequent assessments at different time intervals. A recent evaluation of 16 online tests for Alzheimer's Disease (AD) suggests, however that most online tests have poor reliability and validity, with ethical concerns raised over data collection, privacy and follow-up (Robillard et al).

The QMC

Few self-administered cognitive screens have been validated in clinical practice and those that do, still require supervision. The Test Your Memory (TYM) instrument (Brown et al), the most widely studied self-administered cognitive screen was developed in 2009. Scored by patients, under supervision of trained raters, the TYM was validated in memory clinics against the Mini-Mental State Examination (MMSE), Addenbrooke's Cognitive Examination-Revised (Brown et al), (Hancock et al), and detailed neuropsychological testing (Koekkoek et al). The QMC is the first test validated that be administered by caregivers or patients themselves in an informal setting, without direct clinical supervision. The QMC has excellent accuracy in identifying CI, area under the curve (AUC) of 0.89, compared to the Q*mci* (0.95), and other short cognitive screens including the MoCA (0.71) and MMSE (0.71). MoCA (0.89) and SMMSE (0.89). It also differentiated MCI from NC (AUC of 0.75), compared to the Q*mci* (0.84), the MoCA (0.71) and MMSE (0.71). The QMC also had excellent accuracy in differentiating dementia from MCI, AUC of 0.82.

7.3 Proposal for Cognitive Assessment

The Quick Mild Cognitive Impairment (Q*mci*) screen will be administered at entry into the study and at each interval follow-up assessment to screen for cognitive impairment. The Q*mci* will be administered by trained raters, blind to the study intervention (i.e. blind to which intervention subjects are randomized to: PERSSILAA intervention versus control arm). Subjects who score ≤ 40 will be excluded. Subjects who score less than 40 are unlikely to be able to manage the IT component of the cognitive re-training. The Q*mci* is fully validated against the MMSE, MoCA and ADAS-cog (O'Caoimh et al, 2012, 2013, 2014). On-going assessment of cognition will be based upon self/caregiver administered assessment using the QMC (Quick Memory Check, see Appendix 1). Rates of change in QMC scores over time will be compared for cases and controls.

An app is currently available for the Q*mci* (IOS apple format) in English (see Appendix 1). The Q*mci* is currently translated into Dutch (Q*mci*-D, see Appendix 1). The Q*mci* will also be translated into Italian. As the QMC is based upon the Q*mci* we will aim to quickly develop this into an app in both Dutch and Italian that can be used in conjunction with the cognitive stimulation therapies as part of the cognitive intervention.

Table 13 - Proposed Cognitive screening Qmci cut-off scores for use in PERSSILAA.

Qmci	0 - 49	50-60	60-100
Result	Dementia	Mild Cognitive Impairment	Normal

In summary, given these five key questions listed above, we selected a single short "home" self or caregiver administered screening test and two objective short cognitive screening tests to be scored by trained raters. The Quick Memory Check (QMC), a brief caregiver or self-administered cognitive test, will then be completed by caregivers or patients themselves throughout the course of the study as a means of monitoring cognition. The Quick Mild Cognitive Impairment (Q*mci*) screen, a short neuropsychological test will be completed at baseline and interval follow-up by trained raters in each of the assessment study sites. The AD8 will also be scored if collateral is available. This will represent the core cognitive evaluation. The description of, justification for and methods of using these short screening tests are presented in section 5.4.

8 Screening tools for Nutrition

Poor nutritional status is a major negative prognostic indicator for older adults (van Kan et al, 2008), (Bales, 2001), (Heuberger, 2011), (Bollwein et al, 2013). Weight loss in particular is associated with adverse healthcare outcomes in people >60 years old, regardless of their body mass index (Vermeulen et al, 2011). It is also associated with sarcopenia, anorexia, malabsorption, hypermetabolism, cachexia and dehydration (Mithal et al, 2013), (Bell et al, 2014), (Inzitari et al, 2011), (Ford et al, 2013). Although there has been a significant improvement in our ability to diagnose malnutrition, thanks to the availability of validated tools assisting nutritional assessments (Dent et al, 2012), malnutrition is still underdiagnosed. Malnutrition is common and has a mean prevalence in community dwelling, healthy older adults of approximately 1%. This increases to 4% in those receiving home care, and to 5% in patients with Alzheimer's disease living at home. Malnutrition peaks at 20% in hospitalized patients and at 37% in institutionalized older adults (Bell et al 2013), (Viñas et al, 2011).

8.1 Overview of the existing nutrition screening instruments

The standards for determining nutritional status and the criteria used to define malnutrition are controversial. Indeed, the cut-off scores for defining an individual's nutritional status vary, and reference data are rarely derived from the population that is being studied. Furthermore, due to the variability of methods for assessing nutritional status across studies, it is difficult to compare malnutrition and nutritional risk in either community dwelling or hospitalised older adults (Ferguson et al, 1999), (Guigoz et al, 2002). Nutritional screening targets characteristics associated with nutritional problems, and identify malnourished individuals, or those at risk of becoming malnourished, in order that more extensive nutritional assessments can be performed and interventions implemented where appropriate. The American Society for Parenteral and Enteral Nutrition (ASPEN) have developed a set of criteria which are predictive of undernutrition (White et al, 2012). These include:

- A 10% change in body weight over 6 months or 5% over 1 month;
- A deviation of 20% of the ideal body weight;
- The presence of a disease increasing metabolic requirements;
- Changes in dietary habits due to trauma, surgery, or disease;
- Artificial feeding due to trauma, surgery, or disease;
- Insufficient or inappropriate intake.

Several types of methods to evaluate nutrition are used and many have been compared (Dent et al, 2012), (Skipper et al, 2012), (Söderhamn et al, 2011) in their ability to assess an individual's nutritional status, such as the:

Nutritional Risk Screening (NRS2002)
NRS2002 is a method based on an analysis of controlled clinical trials. This screening tool considers that nutritional support is indicated in patients who are severely ill with increased nutritional requirements, or who are severely undernourished, or who have certain degrees of severity of disease in combination with certain degrees of undernutrition. Patients are scored by (1) undernutrition (body mass index, recent weight loss (%) and change in food intake); (2) disease severity (absent, mild, moderate or severe). NRS score ≥3 is defined as being at nutritional risk (Kondrup et al, 2003). NRS2002 may distinguish the patients with a positive clinical outcome from those with no benefit from nutritional support. This method has been

recommended by The European Society for Clinical Nutrition and Metabolism (ESPEN) for nutritional screening in hospitals among adults. NRS 2002, is an easy tool to detect nutritional risk 72h after hospital admission.

Subjective Global Assessment (SGA)
SGA is an assessment tool that classifies patients subjectively based on features of the history and physical examination. With respect to history the following indicators are evaluated: (1) weight change; (2) dietary intake change; (3) gastrointestinal symptoms; (4) functional capacity, and (5) disease and its relation to nutritional requirements. For physical, loss of subcutaneous fat, muscle wasting, ankle edema, sacral edema, and ascites are assessed (Detsky et al, 1987).
Taking into account the patient's nutritional status the following categories were defined for SGA ranking: (1) well nourished; (2) moderate or suspected malnutrition; and (3) severe malnutrition. This screening tool is used to assess nutritional status of hospitalized surgical patients. On the other hand, since it is a complex tool it is not indicated for rapid screening purposes.

Malnutrition Universal Screening Tool (MUST)
MUST was launched in 2003 by the multidisciplinary Malnutrition Advisory Group (MAG) of the British Association for Parenteral and Enteral Nutrition. It is a screening tool that has been designed for patients at risk of malnutrition in all care settings (hospital wards, outpatient clinics, general practice, the community and in care homes). The following criteria have been used: (1) body mass index; (2) weight loss; and (3) acute disease. The overall risk of malnutrition is given by the sum of the three criteria (Todorovic et al, 2011). A total score of 0 indicates no or low nutritional risk1 indicates moderate nutritional risk; and 2 or more indicates high nutritional risk (Russell and Elia, 2010).

Mini Nutritional Assessment (MNA®)
MNA®, has been developed to assess nutritional status in elderly, has been translated in over 20 languages and recommended by several national and international clinical and scientific organizations. It has been reported as a well validated tool, with high sensitivity, specificity, and reliability (Vellas et al, 2006), being recommended for early detection of risk of malnutrition (Kaiser et al, 2010). This screening tool was validated taking into account clinical status and comprehensive nutrition assessment (Guigoz et al, 2006).
MNA® is simple and can be easily administered by general practitioners and health professionals at hospital or nursing home admission. MNA® highly correlates with clinical assessment and objective indicators of nutritional status (albumin level, BMI, energy intake, and vitamin status), and identifies malnutrition and life-style habits that associate with nutritional risk before albumin levels and BMI are influenced (Dent et al, 2012). MNA® is predictive of outcome and cost of care for outpatients and hospitalized patients, whereas for home care patients and nursing home residents, MNA® correlates to living conditions, meal patterns, chronic medical conditions thus allowing targeted interventions (Chevalier et al, 2008), (Allès et al, 2012), (Thomas et al, 2013).
A clear association between MNA® and Fried's criteria has been demonstrated, and the «nutritional risk» MNA® category is the one most strongly associated with the Fried's frailty index (Jürschik et al, 2013).
MNA® is world widely used to evaluate the nutritional status of elderly patients in clinics, hospitals, nursing homes, or those who are otherwise frail (Guigoz et al, 2006). The full

MNA® includes 18 items: (1) anthropometric assessment (body mass index, weight loss, and mid-arm and calf circumference); (2) assessment (lifestyle, medication, mobility and presence of neuropsychological problems); (3) short dietary assessment (number of meals, food, fluid intake and autonomy of feeding); and (4) subjective assessment (self perception of health and nutrition) (Guigoz et al, 2006). A MNA® indicator score less than 17 points is defined as malnutrition; a score between 17 and 23.5 identifies a risk of malnutrition, and a score over 24 is considered as normal nutritional status. To apply this screening tool it takes around 15 minutes, while the short form of MNA® (MNA®-SF) requires only 5 minutes. MNA®-SF comprises the 6 first items (food intake decline, weight loss, mobility, psychological stress or acute disease, neuropsychological problems and body mass index) of the full MNA®. A MNA®-SF maximum screening score is 14 points. Scores of 12 and above indicate a normal nutritional status without the need to continue the whole assessment; 8-11 points at risk of malnutrition and bellow 7 points it is malnourished (Vellas et al, 1999), (Kaiser et al, 2009). MNA®-SF can identify persons with undernutrition, and can be used in a two-step screening process in which persons, identified as "at risk" on the MNA-SF, would receive additional assessment to confirm the diagnosis and plan interventions (Rubenstein et al, 2001), (Kaiser et al, 2009).

The MNA-SF may be completed at regular intervals in the community and in the hospital or long-term care setting, and is recommended to be done annually in the community, and every 3 months in the hospital or long-term care or whenever a change in clinical condition occurs.
MNA® has also been compared to the other screening tools, in different settings: for example, in a rehabilitation and treatment center for the elderly, two scores of nutritional risk screening, the Nutritional Risk Screening (NRS) and the Mini Nutritional Assessment Short Form (MNA®-SF) validated in the elderly were tested, and the MNA-SF showed a higher sensitivity, suggesting that it might be the reference tool for routine screening in the elderly population. The prevalence of malnutrition risk in a population of older people (aged 75 years and over) attending a community general practice and identify characteristics of those classified as malnourished or at risk of malnutrition has been assessed by MNA®-SF (Winter et al., 2013), one in six were identified as being at nutritional risk which is an additional risk factor for a severe health issue. Importantly, one third of the at-risk group had a BMI in the overweight or obese category, highlighting that older people can be at nutritional risk although they may be overweight or obese.
Finally, MNA® is not only a tool to assess nutritional status but it is also useful in screening populations to identify frail elderly persons (Vellas et al, 1999).

8.2 Proposal for Nutritional Screening

The Mini Nutritional Assessment - MNA® will be the screening method applied for nutrition evaluation. This screening instrument is easy to administer, patient-friendly, and inexpensive requiring no laboratory investigations. It is expected that its implementation can help to prevent and treat early malnutrition, thus enabling the elderly people to enjoy a better health and quality of life. It gives a single and rapid nutrition assessment and was developed to assess nutrition status as part of the standard evaluation of elderly patients in clinics, nursing homes, hospitals, or among those who are otherwise frail.
Up to now this tool is available on line: http://www.mna-elderly.com/default.html and has already been translated in 29 languages (http://www.mna-elderly.com/mna_forms.html). The

validation of the questionnaire takes into account the opinion of 5-6 experts regarding the translation. The MNA® is also available as a free iPhone® and iPad® application in English and French.

This questionnaire provides information regarding: 1) anthropometric measurements; 2) global assessment (e.g. lifestyle, medication and mobility); 3) dietary assessment (e.g. number of meals, food intake and autonomy); and 4) subjective evaluation (self-perception of health and nutrition).

8.2.1 Preliminary Results of Nutritional Screening in Campania (Italy)

In order to examine the nutritional state of the older adult population in the Campania region of Italy and perform a preliminary investigation into the distribution of different frailty related risk factors we performed a pilot study. We administered the MNA® to people undergoing health checks and screenings during Health Campus events in late 2013. This sample is representative of the general population of older adults attending the events associated with the Health Campus, and who were prepared to volunteer for screening. As part of a battery of screens, metabolic and nutritional screening was also performed. Nutritional status was assessed using the MNA®, anthropometric parameters (BMI, waist circumference), blood pressure and capillary blood sugar levels.

In total, 250 subjects completed the MNA®. They had a mean age of 52.9 years (±13.4 years); 27.6% were men. Participants had the following age distribution: 90 were aged between 50 to 60 years of age (of which 21 were men), 120 were aged 51 to 65 years (of which 29 were men), and 40 were above 65 years of age (of which 14 were men).

Nutritional status using the MNA®, where a score < 17 represented ‘malnourished’, scores between 17 – 23.5 ‘at risk of malnourishment’ and scores > 23.5 represented ‘well nourished’, revealed that 48.4% of participants were well nourished, 44% were at risk of malnutrition and 7.6% were malnourished.

9 Screening and Triage Protocol

Based upon the results of the detailed state of the art review described above, investigating possible screening instruments, a screening and triage protocol was developed. As discussed it follows a two-step design using a hierarchical model (described in Section 4.4). In all, we plan to identify approximately 350 community dwelling, older adults age over 65 years who are pre-frail. The figure (**Error! Reference source not found.**) below presents the accepted protocol, providing a general overview of the instruments selected for screening.

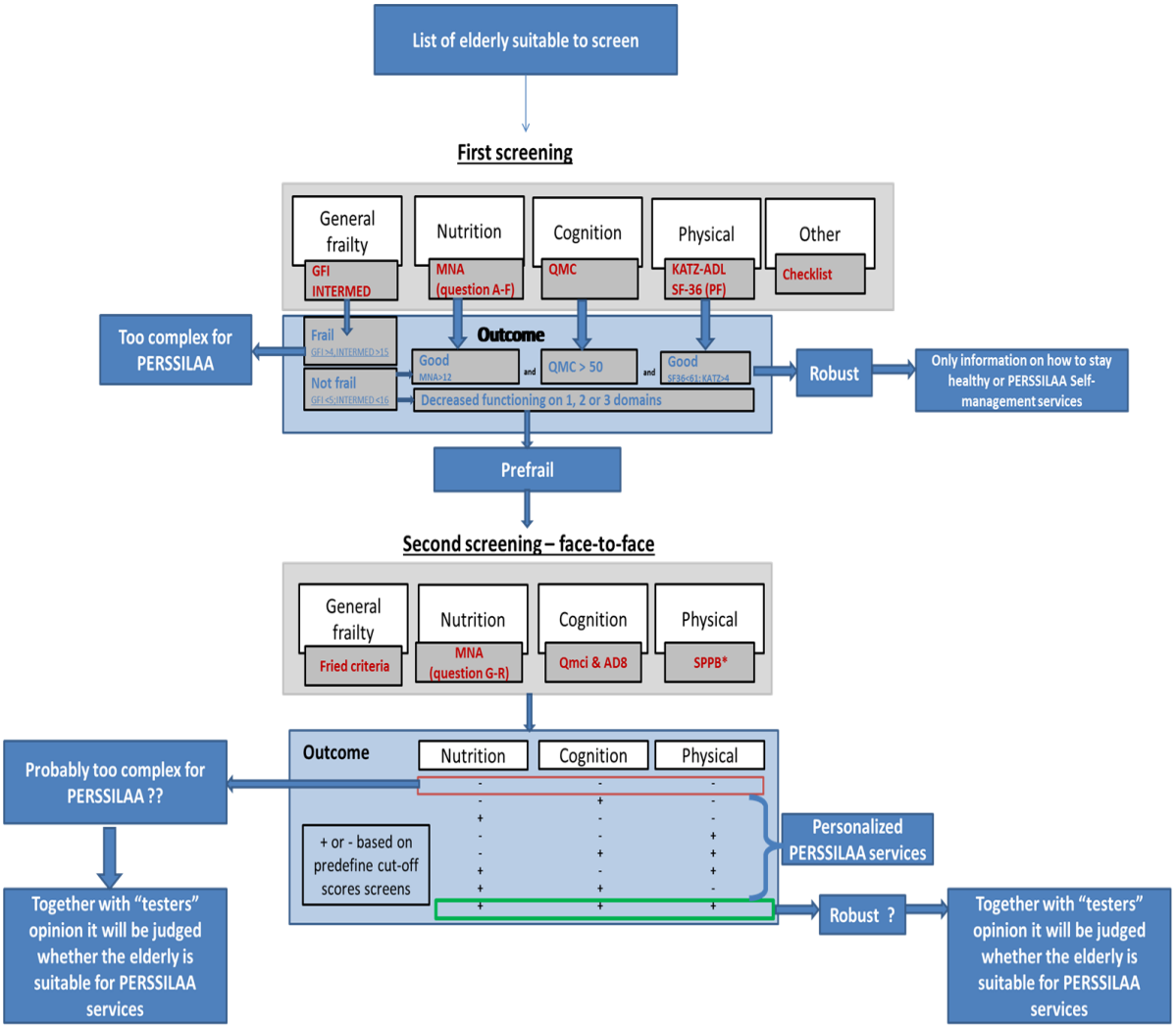


Figure 4 - Proposed two-step screening protocol for PERSSILAA.

All older adults aged over 65 will be eligible for screening. Screening will follow a two-stage approach. The first step will be performed to make a distinction between individuals who are:

1. Too complex for PERSSILAA services (i.e. already frail).
2. Robust and not in need of PERSSILAA training services but might benefit health literacy services in order to stay healthy.
3. Pre-frail. These elderly might benefit from PERSSILAA training services but need further screening and categorization

This categorization will be performed using the following cut-off scores for each of the different domains, using the selected short and home administered screening instruments, presented in Table 14.

Table 14 - Step one of the PERSSILAA two-step screening program: Home administered screening. (GFI=Groningen Frailty Indicator, QMC=Quick Memory Check, MNA=Mini-Nutritional Assessment section A-F).

General Frailty	Nutrition	Physical	Cognitive	Classification
GFI ≥ 4 & INTERMED ≥15	Not relevant			Frail
GFI < 4 & INTERMED < 15	MNA > 12	SF36 < 61 & KATZ > 4	QMC > 50	Robust
GFI < 4 & INTERMED < 15	MNA < 12 or SF36 > 61 or QMC < 50			Pre-frail

Only older adults classified in step one as being non-frail (i.e. pre-frail or potentially normal)_will be invited for a second "face to face" screening, step two, with the aim of identifying true pre-frail older adults at "high risk" of progressing to frailty in order to assign them to the appropriate PERSSILAA service.

The following cut-off points will be used in step two, for each of the categories to classify whether a person shows a decline on a certain domain.

Physical function
For the physical domain older adults will be identified as being:

- Physically fit when an individual scores within the normal range as presented in Table 10 above, on all the four test being performed;
- Physically impaired when an individual scores lower than the normal range on at least one of the four tests.

Cognition
For the cognitive domain older adults will be indicated as:

- Suffering from Dementia if: history of memory loss with Q*mci* 0-40 & AD8 >2.
- Mild cognitive impairment if: Q*mci*: 40-60 & AD8 >2.
- Normal cognition if: Q*mci* 60-100 & AD8 <2.

Note scores will be adjusted for age and level of education as per

Figure 3.

Nutrition
For the nutritional domain older adults will be classified as having:

- Malnutrition if the MNA G-R section total score is less than 17, usually associated with protein caloric malnutrition and low plasma albumin levels.
- Good nutrition when the MNA G-R section total score is over 23.5.

- At risk of malnutrition if the MNA G-R section total score is between 17 and 23.5.

Integrating these three domains together will allow patients to be triaged to one of 8 different personas identified from the screening results as indicated in Table 14 below and presented by different personas in section 10.

Table 15 - Triaging patients for the validation arm of the PERSSILAA project.

	Physical	Cognitive	Nutrition
1	+	+	+
2	+	+	-
3	+	-	-
4	-	+	+
5	-	-	+
6	+	-	+
7	-	+	-
8	-	-	-

In summary, based upon the state of the art literature review undertaken in this deliverable, the PERSSILAA consortium have come to a shared vision on the concept, definition and important screening parameters and screening instruments. Based upon the reviews and consensus discussions undertaken as part of this deliverable it was agreed that PERSSILAA will target approximately 350 pre-frail community dwelling older adults (>65 years) using a two-step screening design. Initial screening will involve a postal/online questionnaire requesting demographic data from community dwellers. This initial questionnaire will be completed at home and the likelihood of frailty will be assessed with the Groningen Frailty Indicator (a 15-point yes-no questionnaire exploring physical, cognitive, social and psychological components of frailty) with additional information coming from the INTERMED questionnaire and the results of three objective home-administered tests, the Quick Memory Check (cognitive), the KATZ activities of daily living scale and the RAND-36 (physical function). Patients with established frailty will be excluded and remaining participants recruited into the second step. This will involve more detailed ”face to face” assessment and stratification of patients at risk of progressing to frailty, including an expert panel review.

Patients who are pre-frail are defined as those with mild dysfunction in any of the three domains:

- cognition (i.e. a Q*mci* score between 40-60, adjusted for age and education, with a history of cognitive decline, but AD8 <2),
- nutrition (MNA G-R of between 7-23.5) and
- physical function (selected cut-off scores on a battery of physical assessments, adjusted for age and gender),
- And a Fried Frailty score of 1 or 2.

Once included patients will be grouped into eight subgroups according to their baseline nutritional, cognitive and physical (specific functional tests including the timed up-and-go test) status for subsequent evaluation in the validation arm of the PERSSILAA project (see Personas in Chapter 10).

10 Personas

The following personas were developed that reflect all possible outcomes of the screening (Table 15):

1. Marja: Robust
2. Li Chan: Nutrition problems
3. Sophie: Cognitive and nutrition problems
4. Cornelis: Physical problems
5. Olivier: Physical and cognitive problems
6. Luuk: Cognitive problems
7. Simone: Physical and nutrition problems
8. Joep: Physical, cognitive and nutrition problems

Marja

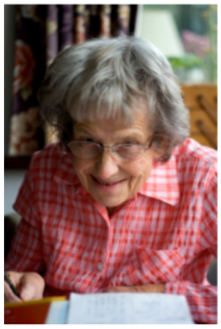
Marja is not intimidated by her age. On her 67th year of life Marja is as busy as she used to be during her 30 years on the job as a nurse. On a normal day, Marja wakes up early, prepares breakfast for her husband Hans, and takes care of her beautiful garden. Around lunchtime, Marja cycles to the market with Hans to buy seasonal fresh products. During the afternoon, depending on the day of the week, Marja either teaches Dutch to immigrants at Het Praathuis or works as a volunteer at Revaladitiecentrum Roessingh. In the late afternoon Marja likes to swim with her friends, followed, of course, by chitchat talk to know the news about each other's families. In the evening comes leisure time: she either reads a book or does some pottery, a hobby started decades ago. The next plan is to join the initiative "Senior Whizzkid" promoted by and for the elderly community in Enschede. This seems a good way to finally get in touch with technology, something that she had been avoiding for the last couple of years. Her husband Hans has asked her sometimes to try out his iPad, but she never wanted to. Next September her oldest grandchild is going to study abroad and Marja doesn't want to lose contact. Marja prefers to ask her General Practitioner about medical issues. They have a good relationship and she trusts her fully. Not that she visits her GP often. There is no real need and she only wants to bother her with important things.

Li Chan

Li Chan, who used to be a farmer, moved to the Netherlands five years ago to meet his son and grandchildren who came here searching for work. Although he doesn't regret his decision, the adaptation has not been easy. 68 years old, Li finds very difficult to learn a new, and so different a language as Dutch. Combined with the homesickness, Li often feels lonely, stressed and anxious. Even simple tasks as grocery shopping can be very tough when you don't know the language, or in his case, most of the ingredients in Dutch supermarkets. Li knows an Asian store but it is far away from home so he often ends up eating leftovers or easy, and not so nutritionally balanced, dried noodles. All these events led to a significant weight loss during the last years. At least Li is a big fan of technology and he keeps in contact with his friends and relatives back in China on a daily basis via his Laptop and Skype. During the last weeks Li started feeling that his body was very stiff. His muscles seem to fail on him especially during the early morning. Because of the language problem, Li is afraid to visit a General Practitioner and he hasn't done so since he arrived in the Netherlands. Furthermore, he doesn't know anything about health, and doesn't want to look dumb. He wants to make a "help call" but doesn't know where to search for help.

Sophie

Sophie, aged 76, has led a fulfilling life as a primary school teacher, but was diagnosed with Mild Cognitive Impairment 5 years ago.. Emma, Sophie's daughter, used to visit her mother twice a month but after the diagnosis she was afraid that Sophie's safety was compromised and decided something had to be done. Emma did want her mother to be independent for as long as possible and so she moved into the guesthouse in the backyard. This way, Emma could provide assistance whenever necessary. To keep a recommended level of physical activity, Sophie is responsible for taking care of the garden in front of the house. However, this task became more difficult after a stomach infection a couple of months ago. For several weeks, Sophie was not able to have a regular alimentation and lost 5 kilos. Lately, she enjoys spending more time playing different games on her personal laptop, like Sudoku or Minesweeper. This was one of the brain stimulation strategies recommended by her General Practitioner in order to avoid worsening of her cognitive impairment to Mild Dementia. Emma does have to start up the laptop and games for her. When it comes to healthcare, Emma arranges everything for Sophie. She knows the regular things about health, Googles any complaints Sophie has, and decides when they will go see their General Practitioner. They like their doctor, but are always critical of his judgment and will provide their own opinion based on what they found online. Emma's stance in deciding whether or not to visit a doctor: "Better safe than sorry."



Cornelis

Cornelis is a 65 year old man who lives in the small village of Geesteren.Cornelis was diagnosed with COPD ten years ago and his health status has worsened since, culminating in two hospitalizations last year. Despite this development, Cornelis refuses stop smoking. He has also been spending most of his day at home on the couch. This and his smoking resulted in a deterioration of his physical capability. During his work as a furniture maker, Cornelis was exposed to an intense scent and dusty environment worsening his condition. Additionally, he suffers from hearing impairment making social interaction extra difficult for him. Besides his poor health condition, Cornelis avoids to seek professional support. He is very skeptical and in his opinion, a visit to the physician is only a way to waste time and money. Cornelis doesn't know a lot about health and, in reality, he doesn't want to know. In any case, he carries his metered dose inhaler in his pocket all the time.

Cornelis used to watch television but now he only follows F. C. Twente matches. He is a passionate fan. Besides that, he tries to avoid any situation that might cause an exacerbation. As a result, Cornelis spends his days painting and drawing the landscape he sees from his window. He rarely visits his grandchildren in Enschede; he feels physically limited and ashamed. Last Christmas, his grandchildren bought him a tablet to try to keep in contact with the grandpa. They claim that they send lots of emails but Cornelis never reads them. Cornelis doesn't know how this modern technology works.

Olivier

Olivier is a bakery owner who lives with his younger sister Lotte in Deppenbroek, Enschede. Two years ago, at age 66, while moving some packages from the storage to the store, Olivier fell on the stairs and broke his left leg. Despite the care of the physical therapist, his physical functioning was never totally restored. During the last months Lotte has started noticing some "memory lapses". Olivier was always very punctual and was known for keeping track of all the orders and deliveries. However, he started missing some important dates. Both clients and suppliers complained that Olivier was not present at appointments. Lotte also noticed that Oliviers mental calculations as cashier were not as fast as they used to be. Whereas before Olivier would rely on his memory, Olivier started using the agenda on his smartphone to help him to be in the right place at the right time. He is a big fan of this technology and carries it all day around. Olivier had always avoided contact with healthcare professionals. Lotte is the responsible for keeping track of regular appointments with the GP and schedule extra ones when necessary. She also motivates Olivier to follow all the recommendations. After one of the regular appointments, Lotte bought crosswords books to help Olivier stimulating his brain.

Luuk

Luuk is a 67-year-old former business consultant in a big IT company in Amsterdam. During his last year as an employee, it started to be troublesome to memorize the names of people around him. A few months later Luuk was diagnosed with Mild Cognitive Impairment, a condition defended by many as a stage between age-related-impairment and dementia. This diagnosis didn't help the transition from employee to pensioner. Luuk often felt empty and didn't know how to occupy his time. Progressively, Luuk got afraid of leaving the house alone. He feels disturbed in overcrowded places. A couple of months later, Luuk decided with his wife Roos that it was time to leave Amsterdam and move to Enschede in search for a more relaxed lifestyle. Every day Roos and Luuk go for a walk at the Volkspark. Here, it's not as crowded as in Amsterdam and Luuk feels more confident. Luuk also joined the tennis club at Twentehallen but after an incontinence diagnosis, he started avoiding these meetings. Now, Luuk occupies his time reading sci-fi books on his Kindle or watching documentaries on Netflix via his Tablet. After moving to Enschede, Luuk found a new General Practitioner. After a first introductory meeting Luuk already has the feeling he can trust her completely. Now, they keep regular contact via email. Luuk feels safe and accompanied in this way.

Simone

Simone is a 72 year old woman with considerably reduced mobility due to balance problems. At home, Simone walks holding the wall, the furniture and handles placed especially by her son Robin. Simone, who used to work at a kindergarten, does not dare to go outside without her wheeled walker. But that doesn't stop her from keeping an active lifestyle. Since her husband passed away, Simone is a volunteer in as many events as possible. However, some months ago Simone had a severe gingivitis what made eating an extremely difficult task. As a consequence, Simone lost 4 kilos and a lot of muscle mass. After this episode, Simone feels weak and spends most of her time at home. Every time mother and son talk on Skype via her laptop, Robin asks if Simone cooked and what she ate during the day. Sometimes Simone avoids answering and John gets worried about her health. Due to her mobility issues, Simone was advised to do physiotherapy twice a week. However, to reach the clinic, Simone has to take two buses and she does not feel confident to do that by herself anymore. It is not possible for Robin drive his mother twice every week and Simone withdrew after the first month. Simone never misses an episode of Dr. Oz on television. This is her main resource of health related information. This strong belief in Dr. Oz led to some discussions with previous GP's. Every time Simone meets her GP, she talks about what she saw on the TV show. John believes his mother is totally capable of living independently at the cognitive level, but if her physical condition does not improve he will suggest a home care facility.

Joep

At 79 years old, Joep is the youngest of three brothers. He used to live with his two brothers at a humble house between Enschede and Boekelo. Here, he performed all kinds of jobs for the farmers around him. He liked living in the middle of nature and riding his bike to one of the urban areas nearby was not a problem. However, the situation changed in the last years after his brothers passed away. Joep couldn't find the motivation to live in the house alone and his health started to deteriorate. First it was a stroke that led to hypertension. Then, and according to some doctors, as a consequence, Joep started having some memory lapses. His only cousin Lisa was the first one to notice during one of her regular monthly visits. The house of her uncle was no longer neat, there was no food in either the fridge or the cupboards, and the weight lost was visible for all of those who wanted to see. Lately, Joep feels particularly weak and started facing some difficulties dressing and bathing alone. Lisa is considering suggesting a home care facility. She is especially worried since her uncle is against all kind of technologies. Sometimes the communication with him is very hard. Joep keeps monthly visits with his General Practitioner in Boekelo. They know each other quite well and have a good relationship. Joep trusts his doctor and is glad when he explains how Joep's physique is changing because of his age.

11 External Review

Expert external raters reviewed PERSSILAAs' screening pathway. Responses were received from three external experts in the Netherlands and Italy, the two validation sites in the PERSSILAA project. In Italy, the review was performed by an expert in the field of geriatrics (professor in internal medicine and geriatrics with an expertise in cardiovascular aging, frailty and physical activity). In the Netherlands the review was performed by people involved in the Dutch Program on Elderly in Groningen "Samenoud" In addition, two expert external reviewers from Spain and Portugal reviewed the entire deliverable and provided constructive criticism. Some of the key points and how they were addressed are detailed below. The questionnaire used in the survey is presented in Appendix 4.

Choice of screening instruments

1. The survey suggested that the experts regarded the selected instruments as being appropriate however, they pointed out that:

- They were unfamiliar with the QMC.
- *We will perform a short pilot study within PERSSILAA to test whether the QMC and its translations can be self-administered.*
- Other short physical screens might be equally useful and perhaps shorter than the SF-36 and KATZ such as the Gait Abnormality Rating Scale (GARS).
- *We are satisfied that there is sufficient overlap to use both the SF-36 and KATZ. In addition, these can be self-administered whereas the GARS requires a trained rater. We will continue to use the SF-36 and KATZ.*
- The EQ-5D+C (Euroqol 5D- cognitive dimension) might be useful for the economic validation.
- *The EQ-5D+C like the EQ-5D measures health related quality of life, but also takes the effects of cognition into account (Wolfs et al). Given that the evidence suggests that the EQ-5D works as well as the EQ-5D+C in those with cognitive impairment (Wolfs et al), and that our target population is those with MCI, we will continue to use the EQ-5D as planned.*
- The addition of the physical domain was considered very useful.
- The addition of a depression screen such as the Geriatric Depression Scale (Yesevage).
- *We are planning to use the ABCS Depression screen. This is a validated shortened version (five versus 30 questions) of the Geriatric Depression Scale, (Molloy et al 2006).*
- The addition of an observer rated instrument to step two of cognitive screening.
- *In response to this criticism, the AD8 was selected, see Chapter 7.*

2. The experts felt that there might be some overlap between the selected screening instruments. They suggested that streamlining of the initial first step of the screening protocol could reduce the burden on the patients themselves and improve the response rate.

We agree and to help streamline the screening protocol we plan to pilot the training protocol among a small sample in both validation sites in the Netherlands and Italy. We will include a

questionnaire in order to obtain feedback from those screened. If redundancy is identified then we will address this by shortening the protocol.

In addition, we agree that concern about the length (time and intensity) of the screening process is a very valid point. We took this into account and will now

- Start screening with the GFI and INTERMED
- Allow older adults, completing online questionnaires to stop and return later, saving their results as they go.
- Provide older adults with feedback including progress reports as they complete the questionnaires

3. Some of the translated instruments would need to be validated in the two validation countries.

We agree and this work is on-going including validation of translated versions of the Qmci (cognitive screen).

4. Clarification of the term pre-frail.

The reviewers rightly pointed out that using Frieds' criteria to define pre-frailty would put too much emphasis on the physical components of frailty. This has been corrected and the Fried criteria will be used to exclude those who are frail. While, pre-frailty will be defined after a review as mild dysfunction in any of the three domains: cognition (i.e. a Qmci score between 40-60, adjusted for age and education, with a history of cognitive decline, but AD8 <2), nutrition (MNA G-R of between 7-23.5) and physical (selected cut-off scores on a battery of physical assessments, adjusted for age and gender), and a Fried Frailty score score of 1 on 2.

5. Suggestions on how to improve the generalizability of the validation study by randomly selecting (inviting to participate) part of the sample were made.

These will be addressed in the validation study.

Thus, several important points were provided by the expert external reviewers and incorporated into the deliverable.

12 Conclusion

In this deliverable, we have discussed the development of the PERSSILAA consortiums' shared vision on screening for frailty. We have also discussed the development of a protocol based upon established frailty risk factors, in order to assess patients and ultimately triage them appropriately into the subsequent validation of the PERSSILAA service model. The review confirmed that frailty has many different definitions. An inventory of these definitions, factors associated with frailty and a discussion among the consortium partners led to an accepted definition of frailty. This definition, derived from the EIP on AHAs' A3 action plan, is practical and complements the goals of PERSSILAA, namely to prevent the development of frailty and subsequent functional decline, while improving healthy life years. According to this definition, frail older adults are those:

"at increased risk for future poor clinical outcomes, such as the development of disability, dementia, falls, hospitalisation, institutionalisation or increased mortality".

This definition takes into account the multi-faceted nature of frailty, which is also reflected in the decision to screen for and intervene on three subdomains of frailty: physical functioning, cognitive functioning and nutritional habits. After inventorying the available screening instruments and deliberation among the project partners, a two-step approach was chosen. This is presented in Figure 8. This screening process aims to identify those individuals who are pre-frail (those who are at increased risk of frailty) in order to offer them training services. Frieds criteria will be used to exclude any remaining frail patients and the remainder will be judged pre-frail by a local expert panel based upon their nutritional, cognitive and physical status. In summary:

First step screening:

General frailty:	- Groningen Frailty Indicator (GFI)
	- INTERMED Elderly Self-Assessment (IM-E-SA)
Nutrition:	- Mini Nutritional Assessment (MNA) → questions A-F
Cognition:	- Quick Memory Check (QMC)
Physical:	- Katz Index of Independence of Daily Living (Katz ADL)
	- Physical functioning subscale of the SF-36-item Health Survey (PF-RAND-36)

Second step screening:

General frailty:	- Fried Frailty Criteria
Nutrition:	- Mini Nutritional Assessment (MNA) → questions G-R
Cognition:	- Quick Mild Cognitive Impairment (Q*mci*) screen & AD8
Physical:	- Balance: timed up and go test
	- Strength: chair-stand test
	- Flexibility: chair sit and reach test
	- Endurance: two-minute step test

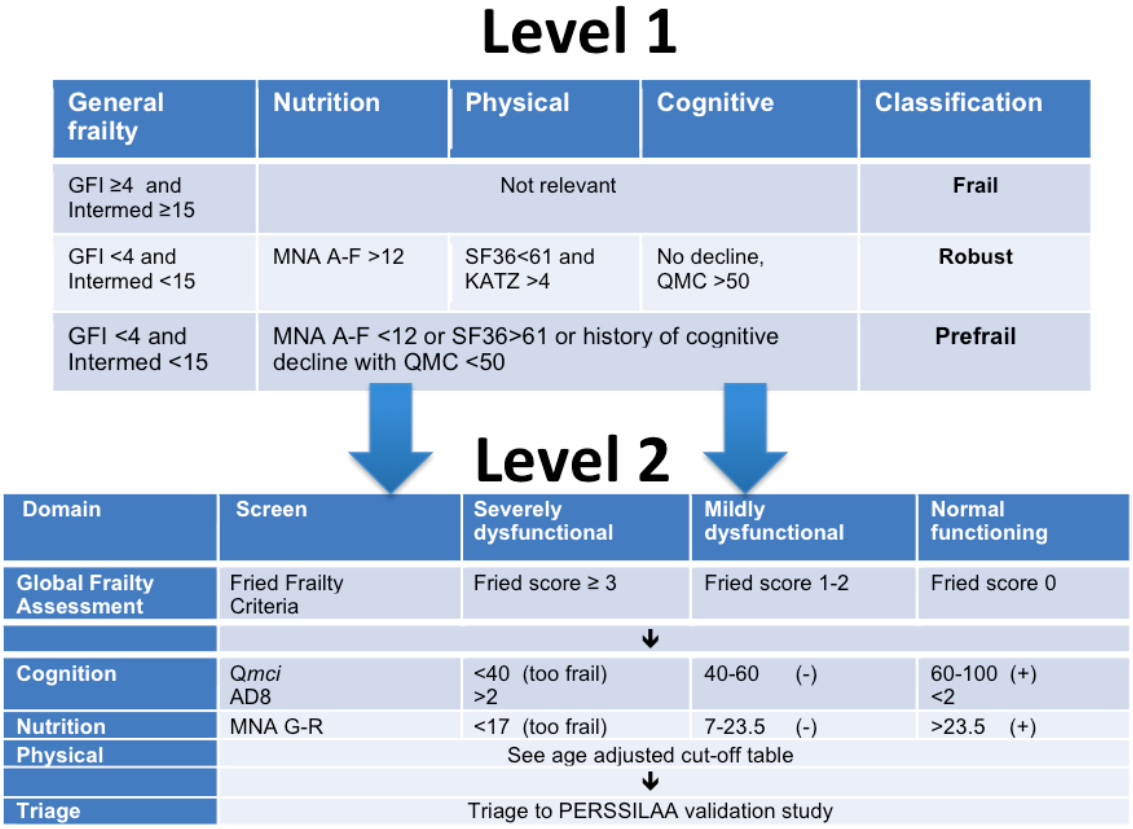
Once patients are deemed pre-frail and suitable for inclusion they will be grouped into eight subgroups according to their baseline nutritional (using the Mini-Nutritional Assessment section), cognitive (using the Quick Mild Cognitive Impairment screen and observer rated AD8) and physical (specific functional tests including the timed up-and-go test) status (see Table 13), in order to evaluate different treatment strategies tailored to individuals need in the subsequent validation arm of the study.
As screening for frailty is most often done by a comprehensive geriatric assessment, involving multiple medical disciplines, the screening procedure we suggest for PERSSILAA marks a great step forward towards creating a short screening and predominantly self-administered evaluation. In the first step, each screening tool can be completed by the older person by him or herself, decreasing workload for volunteers or healthcare professionals, while increases the ease by which participants can complete evaluation by completing much of the screening in their own home and at a time of their convenience.

The second screening is administered by trained professional which, again, is likely to result in a decrease in healthcare professionals' workload. The next step in the PERSSILAA project will be to determining whether older adults are able to complete the self-administered first step screening, and whether or screening is reliable. The latter can, for example, be tested by comparing an individual's score on the second screening with the estimation of the individual's eligibility for PERSSILAA services by the volunteer administering the second screening.

Ultimately, any screening protocol can only be a success when it is appropriately designed, properly implemented and accepted by all end-users and stakeholders. Therefore, the PERSSILAA approach was also developed after obtaining and reviewing feedback from stakeholder meetings in Enschede and Campania. The protocols of these working groups can be found in deliverable D2.2.1: Initial service scenarios, use cases and functional specifications.

The nature of the PERSSILAA project demands that the screening procedure be conducted using ICT "web-based" technology where possible. This imperative has fully been realized in step one of the screening protocol. Here screening instruments were chosen that are easily translated into web-based questionnaires. For the second screening this may not be achievable, as the screening of physical functioning demands on site assessment. As the study continues there may be an opportunity to digitalise this with remote assessment and monitoring. As such, the screening process devised for PERSSILAA marks a step forward towards a digital internet based self-assessment of frailty.

Figure 5 - PERSSILAAs' screening and triage protocol.



13 Future work

Assessment of Reliability and Validation of the screening procedure

The next challenge to ensure the implementation of PERSSILAAs' shared vision on screening for frailty will be the translation and validation of the chosen screening instruments. While most of the instruments are already translated into the required languages; English, Dutch and Italian for the purpose of PERSSILAA study, some will require translation and potentially validation in clinical practice. Progress has already been made on this. Since the start of PERSSILAA, the Q*mci* has been translated into Dutch and Italian. Both translations are being validated in clinical practice. Results from the Dutch validation trial will be available soon.

Once the screening pathways are established, a pre-test and a pilot study exploring the utility of the screening technique will be completed at both sites. The pre-test will focus on the participants' view of the length of the screening and its intelligibility. The pilot test will involve assessing how well participants are able to complete the assessment in their own home and to determine the optimal length of the screening. To this end a random sample will have the home-administered section of the screening protocol (i.e. step one) re-assessed by a trained rater, thereby ensuring adequate inter-rater reliability. A small randomly selected sample will also be asked to repeat the self-administered component at a short interval to assess test-reliability.

Throughout the acceptability of the screening program will be assessed by continuous end-user feedback and assessment.

One of PERSSILAAs' goals is the computerisation of the screening approach to frailty. Step one of the screening protocol realises this through the use of home-administered instruments, each of which can easily be translated into web-based questionnaires. For the second screening this may not be possible, as the screening of physical functioning demands on site assessment. As the study continues there may be an opportunity to digitalise this with remote assessment and monitoring and realise the goal of self-administered frailty screening. The economic potential of this will also need to be explored. This will be discussed in work-up to the validation study.

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Appendix 1 – Selected screening instruments

Frailty

Groningen Frailty Indicator (GFI)

Physical components

1	Shopping	Yes	No
2	Walking around outside (around the house or the neighbors)	Yes	No
3	Dressing and undressing	Yes	No
4	Going to the toilet	Yes	No
5	What mark do you give yourself for physical fitness? (scale 0 – 10)		
6	Do you experience problems in daily life because poor vision?	Yes	No
7	Do you experience problems in daily life because of being hard of hearing?	Yes	No
8	During the past 6 months have your lost a lot of weight unwillingly? (3 kg in 1 month of 6 kg in 2 months)	Yes	No
9	Do you take 4 of more different types of medicine?	Yes	No

Cognitive component

10	Do you have any complaints about your memory	No	Sometimes	Yes

Social component

11	If you are at work, with your family, or at church do you believe that you are part of the social network?	Never	Sometimes	Often	All the time
12	Do other people pay attention to you?	Never	Sometimes	Often	All the time
13	Will other people help you if you are in need?	Never	Sometimes	Often	All the time

Psychological component

14	In the past 4 weeks did you feel downhearted or sad?	Never	Seldom	Sometimes	Often	Very often	All the time
15	In the past 4 weeks did you feel calm and relaxed?	Never	Sometimes	Sometimes	Often	Very often	All the time

INTERMED Elderly Self-Assessment (IM-E-SA)

BIOLOGICAL

1a Chronicity

For how long do you experience any restrictions due to physical complaints (multiple answers allowed)?

- I do not experience any restrictions or I have experienced restrictions for a period shorter than 3 months (item 1.1)
- I have experienced restrictions for a period longer than 3 months of in the past 5 years I have
  experienced several short periods with restrictions (item 1.2)

Do you suffer from one or more long-lasting or chronic diseases (such as diabetes, high blood pressure, rheumatoid arthritis, lung disease or cancer)?

- I don't have a long-lasting or chronic disease (item 1.3)
- I suffer one long-lasting or chronic disease (item 1.4)
- I suffer several long-lasting or chronic diseases (item 1.5)

Calculate score of item 1a 'chronicity' with items above:
0 Item 1.1 and item 1.3
1 Item 1.2 and item 1.3
2 Item 1.1 and item 1.4
2 Item 1.2 and item 1.4
3 Item 1.1 and item 1.5
3 Item 1.2 and item 1.5

1b Diagnostic dilemma

How difficult has it been in the past 5 years to diagnose the physical problems you experience?

- 0 I did not suffer of any physical problem in the past 5 years
- 1 The reason for my problems was immediately clear
- 2 After a lot of investigations the reason for my problems was identified
- 3 Even though a series of investigations have been taken into effect, the origins of my problems were never diagnosed

1c Severity of problems

How much are your daily activities restricted by physical problems?

- 0 My daily activities are not influenced by physical problems
- 1 My daily activities are mildly influenced by physical problems
- 2 My daily activities are moderately influenced by physical problems
- 3 My daily activities are severely influenced by physical problems

1d diagnostic problems

Do you understand the origin of your physical complaints and restrictions?

- 0 I do not have any physical complaints and restrictions
- 0 I understand exactly the origin of my physical complaints and restrictions
- 1 I understand the origin of my physical complaints and restrictions but have some questions

- 2 I understand the origin of my physical complaints and restrictions but have a lot of questions
- 3 I don't understand the origin of my physical complaints and restrictions at all

1e Complications and life treat

<u>In the next 6 months, do you expect your physical health to change? [Try to make the best estimate]</u>

- 0 In the next 6 months I expect my physical complaints or restrictions will be the same or in the next 6 months I still have no physical complaints or restrictions
- 1 In the next 6 months I expect my physical complaints or restrictions to get better
- 2 In the next 6 months I expect a slight worsening of my physical complaints or restrictions
- 3 In the next 6 months I expect a considerable worsening of my physical complaints or restrictions

PYCHOLOGICAL

2a Restrictions in coping

<u>In the past 5 years, how did you cope with stressful, difficult situations?</u>

- 0 Generally speaking, I have always been able to cope with stressful, difficult situations
- 1 Sometimes I had difficulties in coping with stressful, difficult situations, which sometimes resulted in tensions and problems with my partner, family or health care professionals.
- 2 I often experienced difficulties with stressful,difficult situations, which often led to tensions and problems with my partner, family or health care professionals
- 3 I always experience difficulties with stressful, difficult situations. They upset me and make me tense

2b Psychiatric dysfunction

<u>Did you ever have psychological problems, such as being tense, anxious, down/blue or confused?</u>

- 0 No, almost never
- 1 Yes, however without clear influence on my daily life
- 2 Yes and it influenced my daily life
- 3 Yes and these problems have had or still have a long-lasting effect on my daily life

2c Resistance to treatment

<u>Do you think it is difficult to follow your health caregivers' recommendations (i.e. diet, physical activity, life style, medication intake)?</u>

- 0 No, I don't think this is difficult
- 1 Yes, I think this is difficult, but I manage
- 2 Yes, I think this is difficult, so
- metimes I manage, sometimes I don't
- 3 Yes, I think this is too difficult, most of the times I don't manage

2d Psychiatric symptoms

<u>At present, are you experiencing psychological problems, such as being tense, anxious, down/blue or confused?</u>

- 0 No, no psychological problems
- 1 Yes, one or more psychological problems
- 2 Yes, some psychological problems
- 3 Yes, a lot of psychological problems

2e Mental health threat

In the next 6 months, do you expect your psychological complaints to change? [Try to make the best estimate]

- 0 In the next 6 months I expect my psychological complaints will be the same or in the next 6 months I still have no psychological complaints
- 1 In the next 6 months I expect my psychological complaints to get better
- 2 In the next 6 months I expect only a slight worsening of my psychological complaints
- 3 In the next 6 months I expect a considerable worsening of my psychological complaints

SOCIAL

3a Restrictions in social integration

The next question is about activities with you come into contact with other people. You can think about (volunteers)work, study/training, shopping, sports, visiting people or receive visitors

- 0 I have several activities per week that I come into contact with many people
- 1 I have a different activity every week that I come into contact with quite a few people
- 2 I almost always the same activity that I get in contact with the same people
- 3 I have (almost) no activities that I come into contact with other people

3b Social dysfunction

How do you generally relate to other people?

- 0 I have a sufficient amount of contacts with others and socialize well
- 1 I have contacts with others, though every now and then it might become tense
- 2 It is difficult for me to initiate or maintain contacts or friendships with others
- 3 Contacts or friendships often deteriorate into quarrels and conflicts

3c Residential instability

Is your home living situation satisfactory? Or are adjustments needed, such as home modifications, receiving home care, or going to live somewhere else?

- 0 At this moment no adjustments are needed, I can manage my home situation
- 1 At this moment no adjustments are needed, as there is enough support and care by others or I stay in a nursing home
- 2 Adjustments are needed, however not immediately
- 3 Immediate adjustments are needed

3d Restrictions in network

What do you think of the support given by your spouse, family, co-workers or friends?

- 0 I receive sufficient support
- 1 I need some more support

- 2 I need more support
- 3 I receive far too little support

3e Social vulnerability

In the next 6 months do you expect that a change will be needed in the way you are currently living? [Try to make the best estimate]

- 0 In the next 6 months there is no need to change the way I am currently living
- 1 In the next 6 months I am able to stay or return to my current living situation. However homecare is required
- 2 In the next 6 months a temporarily change to another living situation will be needed
- 3 In the next 6 months a permanent change to another living situation will be needed

HEALTH CARE

4a Intensity of treatment

How often have you been in contact with health care in the last five years? (Multiple answers allowed)

- 0 I have had less than four times a year contact with a GP
- 1 I have had four times a year or more contact with a GP
- 1 I have one or more times been in contact with the same medical specialist
- 2 I have had contact with several medical specialists
- 2 I have been hospitalized
- 3 I have been hospitalized several times
- 3 I was more than 7 days admitted to an intensive care unit
- 3 I was more than 6 weeks admitted to a rehabilitation center or nursing home

4b Treatment experiences

How did you experience your contacts with doctors and healthcare providers in the last 5 years?

- 0 I never had problems with doctors and healthcare providers
- 1 I (or someone close to me) had negative experience(s) with doctors and healthcare providers
- 2 I have changed doctors and healthcare providers as a result of a negative experience
- 3 I frequently have changed doctors and healthcare providers because of negative experiences or lack of trust or I was admitted against my will

4c complexity of care

To what extent do your practitioners and healthcare providers work together?

- 0 I do not receive care or just one healthcare worker provides my care
- 0 My doctors and healthcare providers work together well
- 1 My doctors and healthcare providers work together, however sometimes more communication is needed
- 2 My doctors and healthcare providers do not work together quite well, leading to problems every now and then
- 3 My doctors and healthcare providers do not work together

4d Appropriateness of care

Do you think you are receiving enough and the appropriate care from your practitioners and health care providers?

- 0 I do not need any care
- 0 I am receiving the care I need
- 1 I am not receiving any care, but have needs
- 1 I need more of the care I am already receiving
- 2 I need a different type of care
- 3 I need a lot more care or a totally different kind of care

4e

In the next 6 months, do you expect that you will be in need of more help and support? [Try to make the best estimate]

- 0 I expect in the next 6 months that no care is needed or I expect in the next 6 months that my need of care will remain the same
- 1 I expect in the next 6 months that my need of care will become less
- 1 I expect in the next 6 months that my need of care will increase
- 2 I expect in the next 6 months that my need of care will increase and that more coordination is needed
- 3 I expect in the next 6 months that my need of care will increase very much and that much more coordination is needed

Physical Functioning

Katz Index of Independence of Daily Living (Katz ADL)

Katz Index of Independence in Activities of Daily Living

ACTIVITIES POINTS (1 OR 0)	INDEPENDENCE: (1 POINT) **NO** supervision, direction or personal assistance	DEPENDENCE: (0 POINTS) **WITH** supervision, direction, personal assistance or total care
BATHING POINTS:_____	**(1 POINT)** Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity.	**(0 POINTS)** Needs help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
DRESSING POINTS:_____	**(1 POINT)** Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	**(0 POINTS)** Needs help with dressing self or needs to be completely dressed.
TOILETING POINTS:_____	**(1 POINT)** Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	**(0 POINTS)** Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING POINTS:_____	**(1 POINT)** Moves in and out of bed or chair unassisted. Mechanical transferring aides are acceptable.	**(0 POINTS)** Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE POINTS:_____	**(1 POINT)** Exercises complete self control over urination and defecation.	**(0 POINTS)** Is partially or totally incontinent of bowel or bladder.
FEEDING POINTS:_____	**(1 POINT)** Gets food from plate into mouth without help. Preparation of food may be done by another person.	**(0 POINTS)** Needs partial or total help with feeding or requires parenteral feeding.

TOTAL POINTS = _____ 6 = High (*patient independent*) 0 = Low (*patient very dependent*)

Slightly adapted from Katz, S., Down, T.D., Cash, H.R., & Grotz, R.C. (1970) Progress in the development of the index of ADL. *The Gerontologist, 10*(1), 20-30.

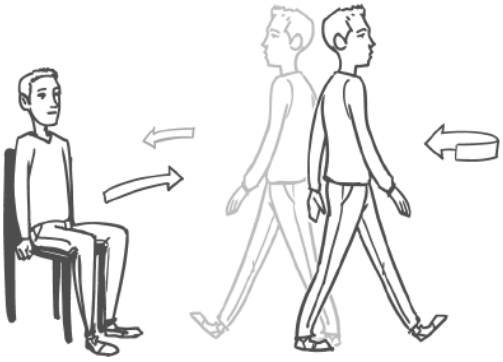
Physical functioning subscale of the SF-36-item Health Survey (PF-RAND-36)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
A. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
B. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?			
C. Lifting or carrying groceries.			
D. Climbing several flights of stairs.			
E. Climbing one flights of stairs			
F. Bending, kneeling or stooping			
G. Walking more than one mile			
H. Walking several blocks			
I. Walking one block			
J. Bathing or dressing yourself			

Physical:

- Balance: timed up and go test

A simple office based test used to identify persons at risk of falling due to balance or gait problems. Individuals should be instructed to rise from a straight backed chair without using their arms. Individual uses his or her cane, walker or gait device and wears shoes. Observe this person walking 10 feet, turning, and returning to their chair. This event should be timed. It has been found that adults without balance problems can perform this test in under 10 seconds. Alternatively, samples of adults with mobility difficulty or ADL dependence require more than 30 seconds.



- Strength: chair-stand test

The test begins with the participant seated in the middle of the chair, back straight and feet flat on the floor. Arms are crossed at the wrists and held against the chest. On the signal "go" the participant rises to a full stand and then returns to a fully seated position. The participant is encouraged to complete as many full stands as possible within 30 s. After a demonstration by the tester, a practice trial of one to three repetitions should be done to check for proper form, followed by one 30 s test trial.

- Flexibility: chair sit and reach test

Starting in a sitting position on a chair, the participant moves forward until she or he is sitting on the front edge. The crease between the top of the leg and the buttocks should be even with the edge of the chair seat. Keeping one leg bent and foot flat on the floor, the other leg (the preferred leg*) is extended straight in front of the hip, with heel on floor and foot flexed (at approximately 90°).

- Endurance: two-minute step test

On the signal "go" the participant begins stepping (not running) in place, starting with the right leg, and completes as many steps as possible within the time period. Although both knees must be raised to the correct height to be counted, the tester only counts the number of times the right knee reaches it. The counter also serves as a spotter in case of loss of balance and ensures that the participant maintains proper knee height. As soon as proper knee height can no longer be maintained, the participant is asked to stop- or to stop and rest until proper form can be regained. Stepping may be resumed if the 2-min time period has not elapsed. If necessary, the participant can place one hand on the table or chair to assist in maintaining balance

Cognitive Functioning

Quick Mild Cognitive Impairment screen (Q*mci*-E): English version
Name: DOB: Years in Education: Date:

1. Orientation (one minute)

(Give 2 points for correct answer, 1 if attempted but incorrect, 0 if no attempt)

What country is this? _____

What year is this? _____

What month is this? _____

What is today's date? _____

What day of the week is this? _____

Score _____ / 10

2. Word Registration (30 seconds)
To begin say…
"I am going to say 5 words. After I have said these 5 words, repeat them back to me. Are you ready?" (Give 1 point per word repeated, in any order, no hints)

Dog rain butter love door

Score _____ / 5

Alternate word groups include…

cat	**dark**	**pepper**	**fear**	**bed**
rat	**heat**	**bread**	**round**	**chair**

3. Clock Drawing (one minute approximately)

"Use the circle provided to draw a clock face, set the time to 'ten past eleven'."
(Give 1 mark for each number, 1 for each hand & 1 for the pivot correctly placed or close to their ideal location. Loose 1 mark for each number duplicated or greater than 12, e.g, 15 or 45, i.e. errors).

Score:	Numbers	Correct	+ _____/ 12
		Errors	- _____
	Hands		+ _____/ 2
	Pivot		+ _____/ 1
		Total	

+ _____/ 15

4. Delayed Recall (30 seconds)

To begin say…
"A few minutes ago I named five words. Name as many of those words as you can remember." (Recall in any order, within 30 seconds, giving **4 points per word**, no hints)

dog **rain** **butter** **love** **door**

Score _____ / 20

5. Verbal Fluency (one minute)
"Name as many *animals* as you can in one minute. Ready? Go."
(Give **half a point per animal named**; to a maximum of 40. Accept all 'creatures' including birds, fish, insects etc. Do NOT count suffixes twice, e.g. mouse/mice but allow points for similar names e.g. calf, cow, and bull. **Alternative forms** include *fruit & veg* or *towns & cities*).

Score _____ / 20

List here, in 'shorthand' if required:

6. Logical Memory (30 seconds)

"I am going to read you a short story. After I have finished reading it completely, I want you to tell me as much of the story as you can. OK?" [patient signifies agreement, then begin reading the paragraph at about 1 second for each word unit until complete]
"The red… fox… ran across.....…..the bushes."
(**Give 2 points per highlighted word**, recalled exactly, immediately within 30 seconds, in any order, no hints. Two alternative stories are provided).

6. Logical Memory			
The **red**	The **brown**	The **white**	2 / 0
fox	**dog**	**hen**	2 / 0
ran across	**ran across**	**walked across**	2 / 0
the **ploughed**	the **metal**	the **concrete**	2 / 0
field.	**bridge**.	**road**.	2 / 0
It was **chased** by	It was **hunting**	It was **followed** by	2 / 0
a **brown**	a **white**	a **black**	2 / 0
dog.	**rabbit**.	**cat**.	2 / 0
It was a **hot**	It was a **cold**	It was a **warm**	2 / 0
May	**October**	**September**	2 / 0
morning.	**day**.	**afternoon**.	2 / 0
Fragrant	**Ripe**	**Dry**	2 / 0
blossoms	**apples**	**leaves**	2 / 0
were **forming** on	were **hanging** on	were **blowing** in	2 / 0
the **bushes**.	the **trees**.	the **wind**.	2 / 0

Score _____ / 30

Q*mci* Total Score _____ / 100

*Mild Cognitive Impairment 40-60/100

Scored by _____Date / /

*adjust for age and education

Quick Memory Check (Q*MC*)

The *Quick Memory Check*

Scoring Instructions:

1. Make sure you have the full attention of the person being tested.
2. Get their permission to carry out the test.
3. Make sure the person being tested can hear you and that there is no background noise or distractions. Get their glasses or hearing aid.
4. Make sure you have a clock/watch to accurately time the test, be strict with time!
5. Don't give clues or feedback regarding their performance. Don't nod or smile when they answer correctly. Don't say, "yes, that's right" or "that was close" or "try again".

To begin say "I'd like to ask you some questions and give you some problems to solve"

		Correct		Score
Q1 <u>Orientation Test</u> **Ask the person...**	**What country is this?** Score 3 points for correct country, accept exact country only.	**Y**	**N**	**/3**
	What year is this? Score 3 points for correct year, accept exact year only.	**Y**	**N**	**/3**
	What month is this? Score 3 points for the correct month or on the first day of the new month or last day of the previous, either.	**Y**	**N**	**/3**
	What day of the week is this? Score 3 points for correct day, accept exact day only.	**Y**	**N**	**/3**
	What is the date? Score 3 points for exact date or ± one day.	**Y**	**N**	**/3**
Q2 <u>Naming Test</u> **Ask them to name as many "animals" they can think of in one minute**. Give 1 point for each, to a maximum 40. *Accept all 'creatures', including animals, birds, fish or insects.* *Do not count repeated names or different suffixes twice e.g. mouse/mice but allow points for similar names e.g. calf, cow, bull.*	**<u>List</u>** Write down each word the patient says, in "shorthand" if fast.	**Number of animals named**		**/40**
Q3 <u>Repeating a Short Story</u> **Once I have FULLY read this short story to you, repeat it for me word for word.** *Give 3 points for each correct word recalled verbatim. Otherwise score 0. Recall may be in any order. Count* ***<u>underlined</u>*** *words only.* **Give a max of 30 seconds for recall.**	"The **<u>white</u>** **<u>hen</u>** **<u>walked</u>** **<u>across</u>** the **<u>concrete</u>** **<u>road</u>.** It was followed by a **<u>black</u>** **<u>cat</u>**. It was a **<u>warm September afternoon</u>**. **<u>Dry</u>** **<u>leaves</u>** were **<u>blowing</u>** in the **<u>wind</u>.**	**Number of words recalled**		**/45**

Total Score:	**/100**

The AD8 Dementia Screening Interview

AD8 Dementia Screening Interview

Patient ID#:_____
CS ID#:_____
Date:_____

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	**YES, A change**	**NO, No change**	**N/A, Don't know**
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. **Daily** problems with thinking and/or memory			
TOTAL AD8 SCORE			

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564

Nutrition

- Mini Nutritional Assessment (MNA) → question A-F

Screening

A Has food intake declined over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties?

0 = severe decrease in food intake
1 = moderate decrease in food intake
2 = no decrease in food intake ☐

B Weight loss during the last 3 months

0 = weight loss greater than 3kg (6.6lbs)
1 = does not know
2 = weight loss between 1 and 3kg (2.2 and 6.6 lbs)
3 = no weight loss ☐

C Mobility

0 = bed or chair bound
1 = able to get out of bed / chair but does not go out
2 = goes out ☐

D Has suffered psychological stress or acute disease in the past 3 months?

0 = yes 2 = no ☐

E Neuropsychological problems

0 = severe dementia or depression
1 = mild dementia
2 = no psychological problems ☐

F Body Mass Index (BMI) (weight in kg) / (height in m^2)

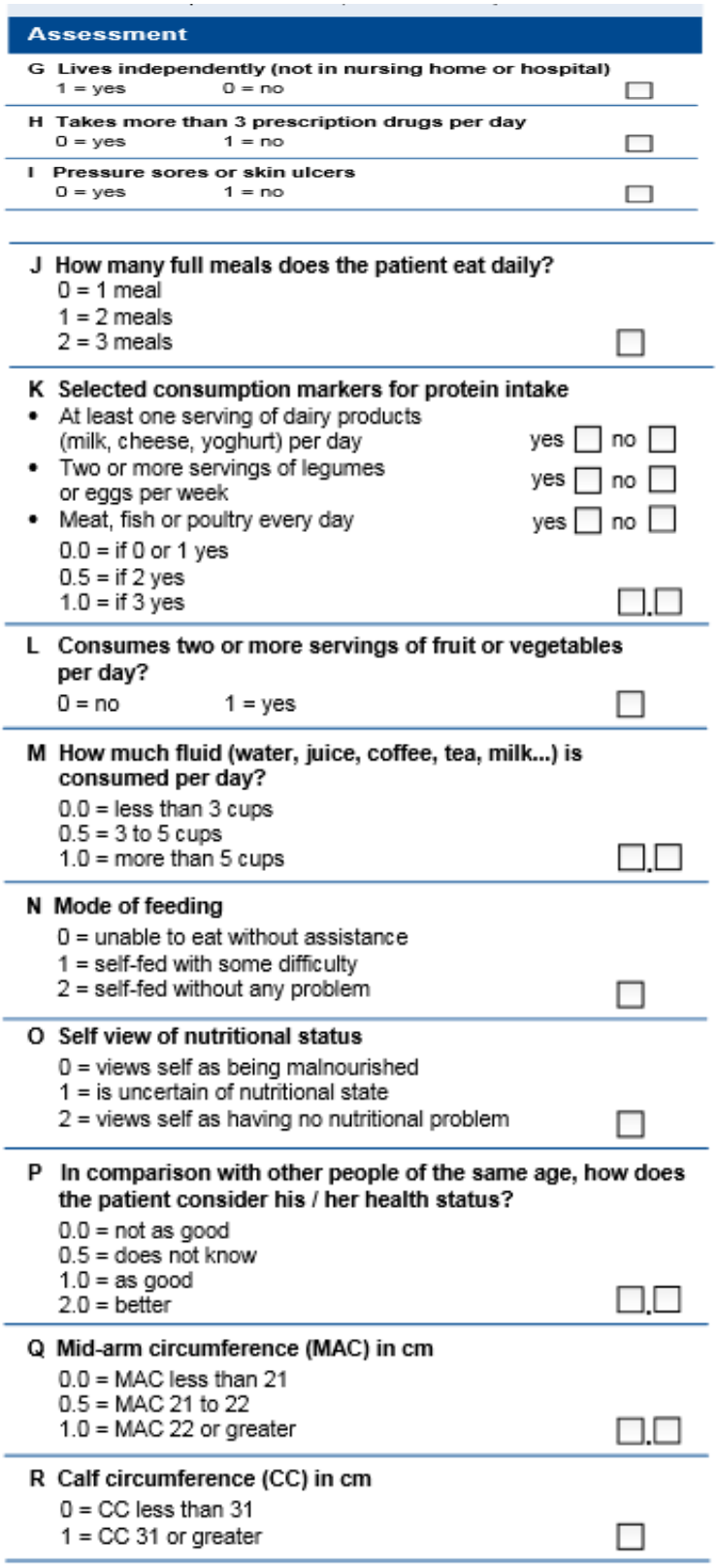
0 = BMI less than 19
1 = BMI 19 to less than 21
2 = BMI 21 to less than 23
3 = BMI 23 or greater ☐

Screening score (subtotal max. 14 points) ☐☐

12-14 points: Normal nutritional status
8-11 points: At risk of malnutrition
0-7 points: Malnourished

For a more in-depth assessment, continue with questions G-R

Mini Nutritional Assessment (MNA) → question G-R



Assessment

G Lives independently (not in nursing home or hospital)
1 = yes 0 = no ☐

H Takes more than 3 prescription drugs per day
0 = yes 1 = no ☐

I Pressure sores or skin ulcers
0 = yes 1 = no ☐

J How many full meals does the patient eat daily?
0 = 1 meal
1 = 2 meals
2 = 3 meals ☐

K Selected consumption markers for protein intake
- At least one serving of dairy products (milk, cheese, yoghurt) per day — yes ☐ no ☐
- Two or more servings of legumes or eggs per week — yes ☐ no ☐
- Meat, fish or poultry every day — yes ☐ no ☐

0.0 = if 0 or 1 yes
0.5 = if 2 yes
1.0 = if 3 yes ☐.☐

L Consumes two or more servings of fruit or vegetables per day?
0 = no 1 = yes ☐

M How much fluid (water, juice, coffee, tea, milk...) is consumed per day?
0.0 = less than 3 cups
0.5 = 3 to 5 cups
1.0 = more than 5 cups ☐.☐

N Mode of feeding
0 = unable to eat without assistance
1 = self-fed with some difficulty
2 = self-fed without any problem ☐

O Self view of nutritional status
0 = views self as being malnourished
1 = is uncertain of nutritional state
2 = views self as having no nutritional problem ☐

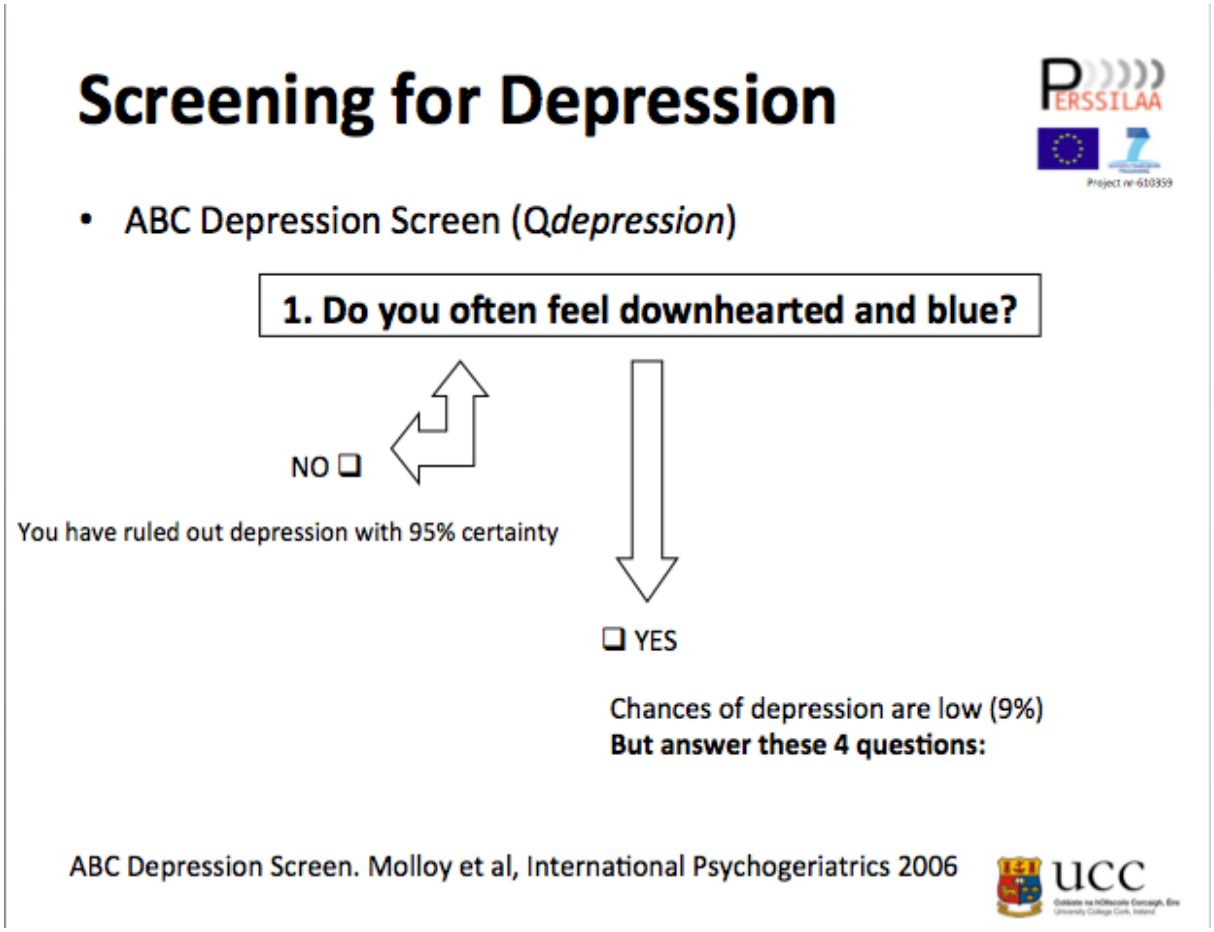
P In comparison with other people of the same age, how does the patient consider his / her health status?
0.0 = not as good
0.5 = does not know
1.0 = as good
2.0 = better ☐.☐

Q Mid-arm circumference (MAC) in cm
0.0 = MAC less than 21
0.5 = MAC 21 to 22
1.0 = MAC 22 or greater ☐.☐

R Calf circumference (CC) in cm
0 = CC less than 31
1 = CC 31 or greater ☐

Other factors

The ABC Depression screen



Scoring instructions for the ABC Depression screen:

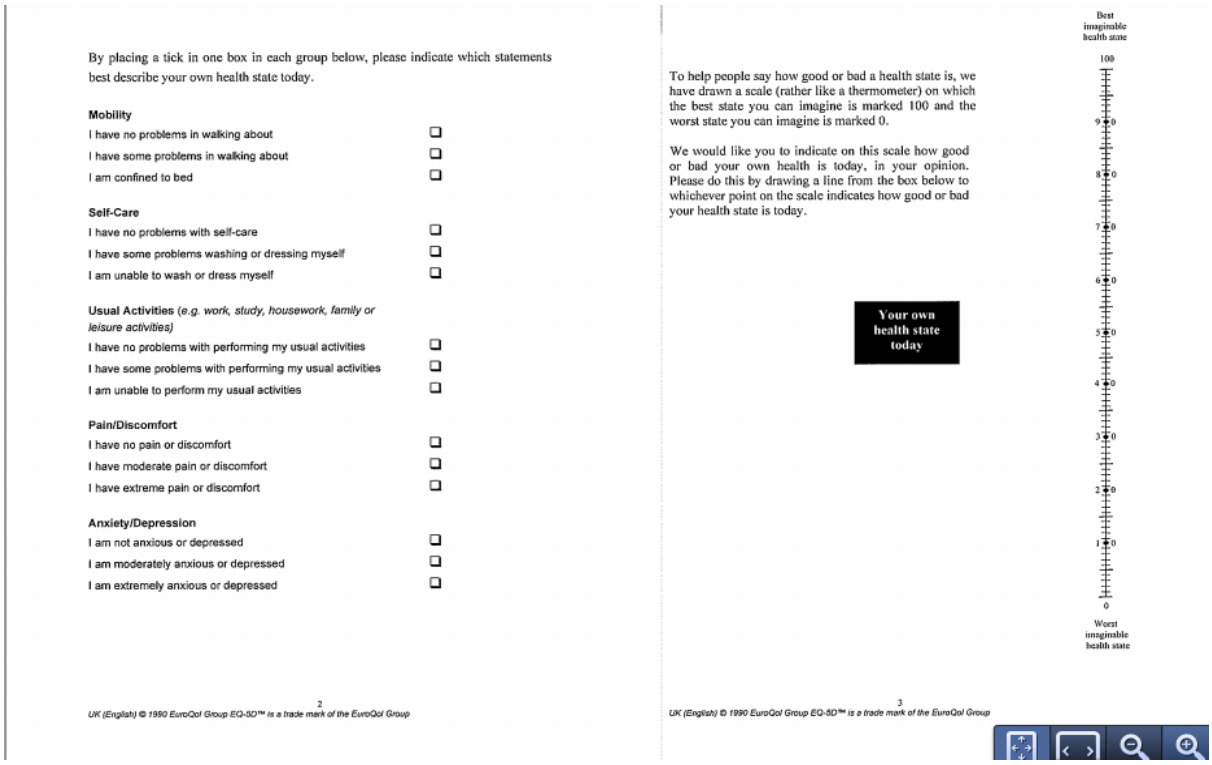
2. Do you feel happy most of the time?	❑ YES	❑ NO*
3. Do you often feel helpless?	❑ YES*	❑ NO
4. Are you basically satisfied with your life?	❑ YES	❑ NO*
5. Do you feel that your life is empty?	❑ YES*	❑ NO

Scoring the ABCDS

*Answers favouring depression **

1/5 has a 6% chance of depression	*Follow up and monitor*
2/5 has a 38% chance of depression	*Follow up and monitor*
3/5 has a 68% chance of depression	***Investigate target symptoms and treat***
4/5 has a 90% chance of depression	***Investigate target symptoms and treat***
5/5 has a 98% chance of depression.	***Investigate target symptoms and treat***

The EUROQOL 5D (measure of quality of life)



By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility
- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am confined to bed ☐

Self-Care
- I have no problems with self-care ☐
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities*)
- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

Pain/Discomfort
- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

Anxiety/Depression
- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

2
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To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today

Best imaginable health state
100
90
80
70
60
50
40
30
20
10
0
Worst imaginable health state

3
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Appendix 2 – Translation tables for personas

Persona	Attribute type	Attribute	Translation
Marja			
	Demographics		
		Age	67
		Education	High vocational
		Physical conditions	Good
		Chronic conditions	None
		Native language	Dutch
		Visual, Auditory, Mobility limitations	None
		Support network	Family and friends
	Technical		
		Computer skills	None
		Attitude towards technology	Has been avoiding technology
		Ownership of technology	iPad
		Use context	At home
		Frequency of use	none
	Healthcare specifics		
		Means used to find out about healthcare	Via GP
		Health skills	Very good as she used to be a nurse
		Current practices in managing health	n.a.
		Attitude towards providers	positive
		Propensity to seek healthcare	Only wants to bother GP with important things

Persona	Attribute type	Attribute	Translation
Li Chan			
	Demographics		
		Age	68
		Education	None
		Physical conditions	Poor
		Chronic conditions	None
		Native language	Mandarin
		Visual, Auditory, Mobility limitations	None
		Support network	Son and grandchildren
	Technical		
		Computer skills	Good
		Attitude towards technology	Positive
		Ownership of technology	Laptop
		Use context	At home
		Frequency of use	Daily
	Healthcare specifics		
		Means used to find out about healthcare	None
		Health skills	None
		Current practices in managing health	None
		Attitude towards providers	Afraid to seek help and afraid to lose face value.
		Propensity to seek healthcare	He wants to seek help but does not know how

Persona	Attribute type	Attribute	Translation
Sophie			
	Demographics		
		Age	76
		Education	High vocational
		Physical conditions	Lost weight due to stomach infection
		Chronic conditions	Mild cognitive impairment
		Native language	Dutch
		Visual, Auditory, Mobility limitations	Wears glasses
		Support network	Daughter Emma lives next door and takes care of Sophie
	Technical		
		Computer skills	Low
		Attitude towards technology	Positive
		Ownership of technology	Laptop
		Use context	At home
		Frequency of use	Daily
	Healthcare specifics		
		Means used to find out about healthcare	Daughter Googles complaints
		Health skills	Normal
		Current practices in managing health	Playing computer games to avoid worsening of her Mild Cognitive Impairment
		Attitude towards providers	Positive, but always critical, based on information they find online.
		Propensity to seek healthcare	“Better safe than sorry”

Persona	Attribute type	Attribute	Translation
Cornelis			
	Demographics		
		Age	65
		Education	Vocational
		Physical conditions	Poor
		Chronic conditions	COPD
		Native language	Dutch
		Visual, Auditory, Mobility limitations	Auditory impairment
		Support network	Children and granchildren in Enschede
	Technical		
		Computer skills	Low
		Attitude towards technology	Avoids technology
		Ownership of technology	Tablet
		Use context	At home
		Frequency of use	None
	Healthcare specifics		
		Means used to find out about healthcare	None
		Health skills	Low
		Current practices in managing health	Carries the metered dose inhaler
		Attitude towards providers	Negative, does not believe in healthcare professionals
		Propensity to seek healthcare	Very low, just when forced to go to the hospital due to an exacerbation

Persona	Attribute type	Attribute	Translation
Olivier			
	Demographics		
		Age	68
		Education	None
		Physical conditions	Poor, broke left leg two years ago an didn't recover completely
		Chronic conditions	First complaints in cognitive level
		Native language	Dutch
		Visual, Auditory, Mobility limitations	None
		Support network	Lives with his younger sister
	Technical		
		Computer skills	Familiar with smartphones
		Attitude towards technology	Always carries his smartphone
		Ownership of technology	Smartphone
		Use context	Everywhere, at any time
		Frequency of use	Daily
	Healthcare specifics		
		Means used to find out about healthcare	Via GP
		Health skills	Normal
		Current practices in managing health	Crosswords for brain stimulation Physiotherapy
		Attitude towards providers	Skeptical
		Propensity to seek healthcare	Avoids healthcare professional; his sister keeps track of the regular meetings and schedule additional appointments when necessary

Persona	Attribute type	Attribute	Translation
Luuk			
	Demographics		
		Age	67
		Education	High Vocational
		Physical conditions	None
		Chronic conditions	Mild Cognitive Impairment; Incontinence
		Native language	Dutch
		Visual, Auditory, Mobility limitations	None
		Support network	Wife
	Technical		
		Computer skills	High, former business consultant in a IT big company
		Attitude towards technology	Very positive
		Ownership of technology	Kindle, Tablet
		Use context	At home
		Frequency of use	Daily
	Healthcare specifics		
		Means used to find out about healthcare	Via GP
		Health skills	Normal
		Current practices in managing health	Brain stimulation through reading
		Attitude towards providers	Positive
		Propensity to seek healthcare	Contact via email whenever necessary

Persona	Attribute type	Attribute	Translation
Simone			
	Demographics		
		Age	72
		Education	Vocational
		Physical conditions	Balance issues; lost weight due to gengivitis
		Chronic conditions	None
		Native language	Dutch
		Visual, Auditory, Mobility limitations	Walker
		Support network	Son
	Technical		
		Computer skills	Good
		Attitude towards technology	Positive, talks to her son regurlarly via Skype
		Ownership of technology	Laptop
		Use context	At home
		Frequency of use	Daily
	Healthcare specifics		
		Means used to find out about healthcare	Television (Dr. Oz)
		Health skills	Normal
		Current practices in managing health	None
		Attitude towards providers	Positive but relies too much on the TV show
		Propensity to seek healthcare	Regular appointments

Persona	Attribute type	Attribute	Translation
Joep			
	Demographics		
		Age	79
		Education	Low
		Physical conditions	Poor
		Chronic conditions	Hypertension, memory lapses
		Native language	Dutch
		Visual, Auditory, Mobility limitations	None
		Support network	Cousin Lisa
	Technical		
		Computer skills	None
		Attitude towards technology	Negative
		Ownership of technology	None
		Use context	n.a.
		Frequency of use	n.a.
	Healthcare specifics		
		Means used to find out about healthcare	Via GP
		Health skills	Normal
		Current practices in managing health	none
		Attitude towards providers	Positive
		Propensity to seek healthcare	Makes monthly visits

Appendix 3 - Glossary

ABC Depression screen: A short five question (yes/no) depression screen, scored from zero (low probability of depression) to five (98% chance of depression). It serves as a screen but will not confirm of exclude a diagnosis of depression (see Appendix 1).

AD8 Dementia Screening Interview
The AD8 (Gavin 2005), (See Appendix 1) is a short informant or self-administered test of cognition. It comprises eight questions detailing the effect of recent change, directly attributable to memory loss, on a variety of daily tasks. Answers can be yes (a change), no or don't know. A score of one point is given for every score answered yes. A score of two or greater is suggestive of cognitive impairment.

Clinical Frailty Scale (CFS): The CFS is nine-point scale, scored from one (very fit) to nine (terminally ill). It can be corrected for people with dementia.
Score one

Cognition: includes the mental processes involved in thinking, rationalizing, gaining knowledge, learning, understanding and decision making. It includes language and imagination. Normal cognition is the state whereby these processes are preserved.

Dementia: Dementia is traditionally defined as memory impairment and difficulty with at least one of the following: Language, coordinating, planning, recognizing, with loss of function (social or occupational). The course of the condition is gradual & persistent [APA criteria/DSM-4] and other causes including delirium have been excluded.

Frail: Multi-factorial state correlating with vulnerability, disability, co-morbidity and self-reported health status: a "State of vulnerability defined by many factors" (Rockwood, 2005 age and ageing). Frail older adults are those who are at increased risk for future poor clinical outcomes, such as development of disability, dementia, falls, hospitalization, institutionalization or increased mortality" (EIP on AHA).

Fried frailty criteria: A short frailty scale based on the assessment of the following parameters (present or absent): Weight loss (>5% in last year), exhaustion, weakness (decreased grip strength), slow walking speed (>6 to 7 seconds for 15 feet) and decreased physical activity (males <383 kilocalories); females <270 kilocalories). Score are categorized as non-frail (score 0), pre-Frail (score of 1 or 2), and frail (≥ 3).

Groningen Frailty Indicator (GFI): A 15 item self-rated questionnaire with four domains; physical, cognitive, social and psychological. A score of ≥ 4 is the cut-off for moderate to severe frailty and exclusion from PERSSILAA (see Appendix 1).

INTERMED: A short 20 item questionnaire screening for risk of frailty which cover biological, psychological, social factors and the extent of recent healthcare usage. A score ≥15 suggests frailty, while a score of <15 may indicate that a patient is pre-frail or robust and thus requires further assessment (see Appendix 1).

Mild cognitive impairment (MCI): MCI is a heterogeneous group of disorders of memory impairment characterized by variable, subtle, cognitive changes with largely persevered function (Peterson). It is often used synonymously with a pre-dementia state with rates of conversion from MCI to dementia approaching 10% per year [Mitchell].

Quick Memory Check (QMC): The QMC The Quick Memory Check (QMC) is a short, caregiver or self-administered test based upon the Q*mci* screen. It includes three subtests. Orientation scored from 15 points, verbal fluency from40 points and LM from 45 points. It is scored from 0 (low indicating cognitive impairment) to 100 points (high indicating normal cognition). The median administration time is three minutes. For the purpose of this study, a cut-off score of >50 for normal cognition is used as an exclusion criterion in level 1 (self-rated).

- **Orientation (Subtest of the QMC):** Similar to the Q*mci* subtest with different scoring: three points are given for each correct answer, zero points for the Administration time is one minute.
- **Verbal Fluency (Subtest of the QMC):** Similar to the Q*mci* subtest with different scoring: one point is given for each word named. Administration time is one minute.

Logical Memory (Subtest of the QMC): Similar to the Q*mci* subtest with different scoring: three points are given for each word correctly recalled from the 15 highlighted words to a maximum of 45 words. Administration time is one minute including the time for word recall.

Quick Mild Cognitive Impairment screen (Q*mci*): The Q*mci* is a short cognitive screen, sensitive and specific in differencing MCI from normal cognition and dementia, scored from 0 (low indicating cognitive impairment) to 100 (high indicating normal cognition) points including six subtests: orientation, working memory, verbal fluency, clock drawing, delayed recall and logical memory.
Median administration time is less than five minutes. A cut-off score (unadjusted for age and education) of <60 for cognitive impairment (MCI or dementia), < 65 for MCI or < 50 for dementia. For the purpose of this study a score of <40 is taken as the cut-off for inclusion after level 2 screening, a score suggesting established dementia (for older patients with lower education).

- **Orientation (Subtest of the Q*mci*):** Awareness of time and place. Composed of five questions: What country, year month, day and date? Patients have one minute in total to answer all questions. 2 points for the correct answer, 1 if attempted but incorrect, 0 if no attempt.
- **Registration (Subtest of the Q*mci*):** Ability to immediately recall five named words. One point is given per word repeated, in any order, within 30 seconds. Alternative sets of words are available. No clues are allowed.
- **Clock drawing (Subtest of the Q*mci*):** A test of visuospatial and executive function: patients are asked to draw a clock on template (blank circle) and to set the time on the clock to “ten past eleven”. One mark is given for each number, one for each hand & one for the pivot correctly placed or close to their ideal location. The subject looses one mark for each number duplicated or greater than 12, e.g, 15 or 45, i.e. errors
- **Delayed Recall (Subtest of the Q*mci*):** A test of episodic memory where the ability to recall the registered words in the ‘registration’ subtest is tested. The words may be recalled in any order, within 30 seconds, giving 4 points per word, no hints.

- **Verbal Fluency (Subtest of the Q*mci*):** A test of semantic memory where subjects are asked to name as many categorical words e.g. animals as you can in one minute. Half a point is given per object named to a maximum of 40 points. All 'creatures' including birds, fish, insects are accepted etc. Suffixes are not counted twice, e.g. mouse/mice are counted as one, but points for similar names e.g. calf, cow, and bull are allowed. Alternative forms are available including fruits & vegetables or towns & cities. No clues are allowed.
- **Logical Memory (Subtest of the Q*mci*):** A test of episodic memory: subjects are asked to immediately recall a short story spoken aloud. It is scored out of 30 points with two points given for each of the 15 words. In total 30 s are allowed for administration and 30 s for response.

Pre-frail: A dynamic state characterized by the risk of developing frailty.

Robust: Active and non-frail.

Appendix 4 – External Expert Review

Dear colleague,

As an expert in your field, we would like to ask you to reflect on a screenings procedure that aims to identify frailty and functional decline among elderly citizens and subsequently, to reduce the level of frailty/functional decline by means of innovative, technology supported interventions. Your knowledge is very important for us, to be able to come to standardization across Europe for assessing and treating frailty, and the related functional decline.

The screenings procedure we ask you to reflect on is developed within the European FP7 project: PERSSILAA (see also www.perssilaa.eu or our Twitter: @perssilaa).

PERSSILAA aims to develop and validate a new service model to screen for, and prevent frailty and functional decline in community dwelling adults. In specific, we will focus on the cognitive, nutritional and physical domain. PERSSILAA service model discerns itself from other programs by its use of technology. Internet technology is used whenever possible during the screening for, and prevention of frailty and functional decline. Of course, for those that are unable to use these technologies, the same services will be offered in a traditional, face-to-face setting.

Basically, the PERSSILAA service model entails the following parts: screening for frailty and functional status, monitoring of functional decline, and training of those who show decreased physical functioning, cognitive function and/or malnutrition. At this stage of the project, we are developing the screening procedure. We would very much like to hear your thoughts on our initial plans. We would appreciate it if you would comment on the screening instruments we have selected for the screening and the associated triage. With your help, we can improve upon our selection or triage model or, if you think this is a fine selection, we will know we are on the right track. In addition, your feedback is important for us in order to increase the chance on European standardization. In order to give us feedback we provide you with the following information: an explanation of the triage, a set of screening instruments, and a short questionnaire

We would like to thank you very much for your time. If you have any questions, you can always contact Prof. dr. Miriam Vollenbroek-Hutten (project coordinator; m.vollenbroek@rrd.nl) or dr. Lex van Velsen (l.vanvelsen@rrd.nl). You can return the questionnaire via email to one of them. Or, you can send it by post to Lex van Velsen, Roessingh Research and Development, P.O. box 310, 7500 AH Enschede, the Netherlands.

Kind regards on behalf of the PERSSILAA team,

Prof. dr. Miriam Vollenbroek-Hutten
Dr. Lex van Velse

Survey

First, we would like to ask you some questions about yourself:

Name:		
Name organization:		
Organization type:	☐Hospital ☐Research institute ☐University ☐Other, namely:	
Location of organization:	Place:	Country:
What is your function at this organization?		
What is your main expertise?		

Next, we would like to ask you a set of questions about the instruments and triage in PERSSILAA:

If you feel unqualified to judge all of the instruments that are proposed in PERSSILAA, please indicate on which instruments you have focused for answering the questions below.	
Overall, what do you think of the screening instruments that are proposed in the screening in PERSSILAA?	
Do you think there is too much overlap between the screening instruments? If so, between which ones?	
Is there an instrument that you are missing? Or is a specific variable that you think that needs to be assessed missing?	
Given the context of the PERSSILAA project, do you think the selected screening instruments are the best instruments currently available for each domain? If not, which one is, or which ones are and for what reason?	

Overall, what do you think of the triage that is proposed in PERSSILAA?	
Do you think the cut-off points (i.e., the test outcome scores that lead to a second screening or recommendation to use an online intervention) are well chosen? If not, which ones need to be redefined, and why?	
Do you have any other remarks or suggestions?	

We would like to thank you very much for your time. If you have any questions, you can always contact Prof. dr. Miriam Vollenbroek-Hutten (project coordinator; m.vollenbroek@rrd.nl) or dr. Lex van Velsen (l.vanvelsen@rrd.nl). You can return the questionnaire via email to one of them. Or, you can send it by post to Lex van Velsen, Roessingh Research and Development, P.O. box 310, 7500 AH Enschede, the Netherlands.